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Human Rights and Mental Illness:

An investigation into the meaning and utility of rights for people
diagnosed with mental illness

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Abstract

This study sought to develop an understanding of the ways in which rights are conceived of and made use of by people diagnosed with mental illness. This research sheds light on the processes involved in actualising rights in the lives of people diagnosed with mental illness. It focuses on the experiences of people diagnosed with mental illnesses living in the community.

Focus groups were conducted with people diagnosed with mental illness who were currently living in the community. The method was informed by some of the principles of action research. The purpose behind the use of focus groups was to provide some insight into the process of negotiation and debate which seemed to be a feature of the way individuals make sense of their rights. The action research orientation reflected a concern for the issue of power, both in research with a marginalised sector of the population and in the context of the lives of participants.

The analysis provides some insight into the ways in which the experiences of people diagnosed with mental illness exert an influence on their understandings of their rights, what they are entitled to, and the opportunities and challenges they identify in actualising these rights. What seems clear is that the participants view rights as a means of challenging the exclusion to which they feel subjected, and as a means of asserting their equality. Yet, in actualising their rights, the participants seemed to struggle to hold onto their sense of what they were entitled to, particularly at the level of interpersonal interactions with friends and family members. What the research also revealed was that issues of identity were tied up with the act of claiming one's rights. It is suggested that experiences of discrimination and internal feelings of doubt mitigate the actualising of rights. The implications for the practice and

application of rights are briefly considered.

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Chapter 1

Introduction

Any research involves an interaction between the interests of the researcher and issues in society that are framed as social problems and consequently warrant investigation. This chapter proceeds as a point of entry into consideration of these issues. I begin with a brief account of the aims and rationale for this research. This chapter also includes an overview of the structure of the thesis.

In many parts of the world, including South Africa, the issue of human rights occupies a significant space in public discourse. This broad awareness of 'human rights' has as one of its main aims the protection of all citizens from abuse. Creating laws to protect these rights and making those who may potentially violate the rights of others aware of the implications are some ways in which a society could seek to protect its citizens. More importantly however, the perceived value of a broad awareness of human rights lies in allowing individuals and groups to use their knowledge to claim their own rights and be vigilant to any attempts to violate these. To understand the process of how rights are asserted, it becomes necessary to consider the meaning and significance these rights have for people who are protected by them. The ways in which groups of people, particularly those vulnerable to human rights abuses, understand and interpret their rights becomes important in getting a sense of how 'rights' are used to protect members of society. Those diagnosed with a chronic mental illness constitute a group who are vulnerable to having their rights abused, due to years of abusive medical practices and social stigmatisation (Emerick, 1996; Gendreau, 1997; World Health Organisation, 2001a, para. 2). I have chosen to use this group for the purpose of this research.

Mental health is a function of a complex array of social, biological, environmental and psychological factors (WHO, 2001b, chap. 1). Included among the severe mental health problems are illnesses such as depression, schizophrenia and other psychoses. The field of mental illness is a somewhat contested terrain, with arguments being made that the concept is a myth on the one hand, (Szasz, 1972) and a biological, rather than a mental problem, on the other. However, there can be no doubt that those who are diagnosed with these kinds of illnesses very often exhibit bizarre thoughts and behaviours, and experience varying levels of subjective distress. In addition, they are subject to various forms of discrimination and stigmatisation, although the ways in which these are expressed are context-bound. The World Health Organisation identifies four key issues in relation to the rights of those diagnosed with mental illness. These are in the area of access to treatment; the quality of the treatment, including the quality of living arrangements; the discrimination and stigmatisation which affects many areas of their lives; and the effects that the foregoing have on their ability to claim their rights (WHO, 2001c, chap. 4.).

It is the area of stigmatisation in particular which is the focus of this study. Recently, mental health care in South Africa has been in the process of undergoing a move from institution-based care to care in the community - a move termed 'deinstitutionalisation.' As this transformation unfolds, it becomes likely that the increased number of people diagnosed with a mental illness living in the community will lead to increased tension between the community and such people. There is thus the likelihood that there will be a greater need for people diagnosed with mental illnesses to assert and enact their rights within the community. In discussing the process required to assert their rights, it is not possible to ignore the reality of social discrimination against them and the possibility that its internalisation might limit

their ability to claim their rights.

Aims

This study seeks to investigate the way rights are negotiated in the lives of those diagnosed with a mental illness. The focus is on the ways in which being diagnosed with a mental illness, and the responses of others to one's diagnosis, affect the meanings which are ascribed to rights. This larger question makes several assumptions that a study of the literature brings out. The first is that rights are not universally defined and understood. This implies that there are certain contextual and experiential factors that influence how people make sense of their rights. In the current context, this translates into an examination of the experiences that surround being diagnosed with a mental illness, and living in the community with that diagnosis. In other words, the subjective meaning 'rights' have for those diagnosed with mental illness, the possibilities they envisage for themselves within these and the challenges they experience in enacting their rights. In order to arrive at such an understanding, this thesis focuses on the following interrelated questions.

1. How do people diagnosed with mental illness define themselves and their place within society?
2. What dimensions of rights are important to them?
3. How do they envisage their rights in a variety of everyday contexts, such as work, close relationships and family interactions, as well as in contact with the health care system?
4. How do they describe the difficulties and possibilities of claiming their rights in these various settings?

Historically, the focus of research into mental illness has focussed on particular aspects of the illness, or on ways to treat those who suffer from the illness. This has the effect of positioning the person diagnosed with a mental illness as a problem to be solved, giving primacy to their diagnosis and ignoring their existence as people. This study makes use of focus groups to access aspects of experiences related to being a person diagnosed with a mental illness. In adopting this method, I seek to redress some of the marginalisation of this particular experience of disability.

Motivation for the study

There are a variety of reasons behind the choice of this particular field of study. Broadly speaking, mental illness as a subject for research was based on my personal interest in the field, as well as the impact mental illness has on the lives of a significant proportion of the population. Mental illness is one of the biggest threats to global health, affecting around 450 million people globally. "One in four people will suffer from a mental or neurological disorder at some point during their lifetime." (WHO, 2001a, para. 1). For this reason, mental health and mental illness are areas of concern for anyone interested in the field of health generally. More particularly, my interest in the field was sparked by volunteer work conducted in a psychiatric hospital.

The reason for focussing on rights was due in part to the growing importance the idea of human rights has come to have internationally in the last fifty years. In South Africa, the issue of human rights has been of central importance in both the struggle against Apartheid and in the creation of a new democracy. The South African Constitution foregrounds rights in the Bill of Rights, which is the second chapter of that constitution. My interest in human rights was borne out of a fascination with the paradoxes evident in a situation in which the

country is in the process of moving towards democracy, at least on a visible, political level, yet, at the level of ordinary people's lives, there are questions over how much has actually improved. This gave me the sense that possibly the proliferation of rights and the central place which rights seem to occupy in our public discourse might be failing in the achievement of the objective of improving the lives of the citizens of South Africa. To the extent that this might be true, this research is an attempt to understand some of the reasons for this, at a micro or interpersonal (and indeed intra-psychic) level in the lives of people diagnosed with mental illness.

The value of developing a greater understanding of the way human rights are made use of by people diagnosed with mental illness is that this information can then be used to inform programs aimed at educating people diagnosed with mental illnesses about their rights. If they better understand their rights, they are likely to be able to assert them more strongly. This idea was both one of the motivations for the research and informed the action research orientation of this research.

It has been suggested that South Africa needs to move towards greater recognition of the rights of the mentally ill in the mental health system (American Association for the Advancement of Science, 1998; Robertson, Zwi, Ensink *et al*, 1997). To this end, a new Mental Health Care Act is in the final stages of the legislative process, and was due to be passed before the end of 2001, although at the time of writing (2002) this piece of legislation is still in process. In this bill, there is a chapter specifically devoted to the issue of rights (see Appendix), and the Bill has been characterised as representing a more rights-based approach to mental health care (Freeman, 2001). The other important feature of the Bill is that it encourages a shift to deinstitutionalisation, in the method of care and treatment of people

diagnosed with mental illness.

Deinstitutionalisation is the move from institutionalised care to care and treatment of people diagnosed with mental illness in the community. It is a move which has been growing in popularity worldwide since the 1950's, but which, in South Africa, is a relatively new development. It was made possible largely by the development of psychotropic drugs which help to control the symptoms of many mental illnesses. The deinstitutionalisation movement has been rationalised as reflecting a greater awareness of the rights of those diagnosed with mental illness, and consequently it should be examined in the light of this. Again, the issue that arises is, given the increased concern for human rights issues in mental health care, how do those diagnosed with a mental illness understand this issue?

Deinstitutionalisation will also lead to increased numbers of people diagnosed with mental illnesses living in the community. This suggests that there will be an increased need to examine the ways in which the community responds to these people. The suggestion that there is widespread discrimination against those diagnosed with mental illness (WHO, 2001a, para. 2) implies that the issue of human rights as it pertains to community care will need to be examined very carefully. In particular, the rights of the mentally ill are no longer just the concern of the mental health care system, but become relevant in the community as well. An investigation of the ways in which human rights, the community and the mentally ill interact would perhaps shed some light on this subject. One of the most constant characteristics of deinstitutionalisation is the provision that those diagnosed with a mental illness should be hospitalised if their behaviour is viewed as a threat to members of the community. This is a human rights issue, as it positions the rights of the person diagnosed with a mental illness to refuse treatment, and to liberty in general, in opposition to the right of the community to be

protected from harm. As such, deinstitutionalisation makes the rights of the mentally ill an increasingly salient issue for society.

Deinstitutionalisation also encourages debate about rights issues, because it brings into sharp relief the needs of the 'patient', and the ways in which these needs interact with the family and its needs, as well as the community's needs. Yet, even the greater debate about the rights of the person diagnosed with a mental illness, which deinstitutionalisation and related concepts has brought about, has focussed on the rights of the person *qua* mental patient, rather than as a person in society. This seems to be something of an oversight, and it is this with which this study seeks to engage. Deinstitutionalisation results in larger numbers of people residing in the community. It is consequently suggested that issues related to rights to appropriate treatment and/or institutionalisation are only one part of the rights debate, and may not prove to be the most significant for those people diagnosed with a mental illness. The fact that there will be more people diagnosed with mental illness receiving their treatment in the community suggests that there is a need to investigate the experiences associated with actualising rights in an everyday context.

The mental health care system in South Africa is in the process of being integrated into the primary health system, as a function of deinstitutionalisation. What this effectively means is that the majority of patients are likely to receive their treatment from community primary health clinics (Swartz & MacGregor, 2000). The aim is to reduce the amount of time spent in an institution, and minimise the disruption that each period of institutionalisation causes to the life of the mentally ill person. However, patients living in the community will continue to meet with a psychiatrist at regular intervals, to assess their progress and make treatment modifications where necessary. Despite the focus on community care, it is expected that the

institution will remain a part of the mental health system, providing treatment for those in acute or psychotic phases of their illness. For this reason, despite the focus on the experiences of people with mental illnesses living in the community, their experiences and understandings of their rights in relation to the institution, and the mental health system as a whole, remain of interest.

Structure of this thesis

In Chapter 2, I provide an analysis of the concept of rights, including certain aspects of the debate about rights in general that are relevant to the discussion of rights in this context. This will also involve a discussion of the ways in which rights for those diagnosed with mental illness have been conceived, pointing to some of the areas of debate. The objective of this process is to provide the reader with some sense of the ways in which those engaging in research have sought to define the issue of rights in the context of people diagnosed with mental illness. This will provide a background with which to contrast the way in which those diagnosed with mental illness understand human rights. Given the aim to investigate some of the contextual factors associated with being a person diagnosed with a mental illness, certain ideas around being a mentally ill person in the community will be examined in Chapters 3 and 4. In particular, some ideas from the field of disability studies will be considered. Mental illness falls within the wider category of disability. Chapter 3 explores some of the ideas about disability as a form of oppression, in particular the social exclusion which is felt to be a common experience of those with impairments. This chapter also contains a consideration of some of the implications for an investigation into the rights of people diagnosed with mental illness. Writers on the subject of oppression in various fields, such as Fanon (1967: 1993) and Bartky (1990), have also suggested that the psychological consequences of such oppression be examined. These ideas will be considered in Chapter 4.

Chapter 5 deals with issues of methodology. For the current study, with its focus on the ways in which meaning is developed, it was felt that a method that offered insight into the interaction and negotiation of meaning would be desirable. For this reason, a *focus group method* was adopted. This research also has, as one of its broader concerns, an interest in issues of power, for example in relation to the question of who has the power to set a rights agenda for those diagnosed with a mental illness. As such, it was felt that a method that made issues of power salient was desirable. For this reason, this research sought to espouse some of the ideas of *action research*, with its concern for empowerment and the diminishing of power differentials within the research process. The method chosen for the analysis reflected the concern for meaning that is at the heart of this research. Consequently, an interpretivist method was employed.

The themes and ideas that emerged from the group interactions are considered in Chapter 6. An attempt was made to include large sections of the actual transcripts in this chapter. The aim was to allow the voice of the participants to come through in the research text. This was done as a way of attempting to challenge the absence of the perspective of the person diagnosed with a mental illness from research into issues that affect their lives.

The discussion in Chapter 7 draws attention to certain dimensions of the experience of those diagnosed with a mental illness. Particular attention is paid to the ways in which others respond to those diagnosed with a mental illness, the feelings that these responses evoke on the part of the participants, and the ways in which the participants deal with these responses on the part of others. The implications for rights are considered, as are the participants' ideas about rights. Chapter 7 also contains some final conclusions.

Chapter 2

Theoretical Orientation I: The Legal and Moral Dimensions of Rights

Initially, it is necessary to begin with an examination of what is meant by the concept of rights, to define it, and to identify its origins. It will then become possible to point out some of the practical and philosophical issues in the field of ‘rights’ generally, and in human rights in particular. I emphasise human rights, because traditionally, there has been a division between moral rights, which are the basis for ‘human rights’ in the everyday sense, and legal rights, which are rights defined by the field of law. (Wellman, 1997; Drewett, 1999). This in turn provides the basis for a consideration of the rights of people diagnosed with mental illness, particularly as this applies to South Africa.

Understanding Human Rights

A human right is a conceptual device, expressed in linguistic form, that assigns priority to certain human or social attributes regarded as essential to the adequate functioning of a human being; that is intended to serve as a protective capsule for those attributes; and that appeals for deliberate action to ensure protection.

(Freeden, 1991, p. 7)

Several issues deserve mention in this regard. The first is that this definition highlights “adequate functioning”. In a sense, human rights are designed to ensure that what is common to all people is respected and promoted. For this reason, many documents set out codes of rights emphasising human dignity, etc. This definition also brings to attention autonomy, in the description of a protective capsule. Wellman has termed it a “sphere of dominion” (Wellman, 1997, p. 42). Rights are meant to function to protect individuals from interference within certain areas, within which they have a ‘right’ to make decisions for themselves.

Indeed, the first document specifically detailing what are now thought of as human rights, the Declaration of the Rights of Man, was developed as a response to the need to protect individuals from arbitrary interference by the State (Bobbio, 1996). The precise areas that are to be protected, as signified here by the idea of “attributes”, are defined by various Bills of Rights, and other documents, and consequently are dependent on the context within which they are being examined.

Bobbio (1996) has divided the development of human rights into three periods. The first stage is characterised by liberty rights, the rights associated with non-interference in the affairs of individuals by the state. Political rights characterise the next stage, where the emphasis shifts to autonomy, or a positive conception of freedom, in which individuals are involved in the political developments within the state. The final phase, which Bobbio suggests we are currently moving towards, is the phase that emphasises social rights. This phase has as one of its underlying assumptions the idea that the power of individuals to affect developments within the state is negatively affected by poor socio-economic conditions. Thus, the state has a duty to enhance the capacity of people to assert their rights. This seems to suggest that the issue of capacity to assert one's rights is an issue for those seeking to develop an understanding of human rights.

Rights, in the sense of human rights, have been traced to the concept of natural law. As such, they were felt to be the rights which all men (and later all women) possessed in a mythical state of nature (Tuck, 1989). It was this line of thought which came to have a prominent role in the creation of documents such as the Declaration of the Rights of Man and the Citizen in France, drawn up in 1789, as well as the 1789 Bill of Rights in the USA (Glendon, 1991). These documents served as rallying points for those involved in the American and French

Revolutions. In this way, the notion of human rights was influential in the formation of what are now liberal democracies. They occupied a significant space in the founding discourse of most modern states, because they emphasised the *right* of individual citizens to have a say in the running of the country, through the election of members of the government and as such their influence has been evident from the start. As Strong (1980) explains, “the logic of the republican argument is that human beings are not fully human if they live in circumstances in which they are unable to exercise these (rights)” (p. 36). Thus, the emphasis was on civil and political rights, and spoke to what constituted a ‘citizen’ viz. a citizen is someone having the civil right to elect members of the government. In South Africa, human rights have served as a founding principle for the new democratic state, and in some ways represent the fundamental difference between South Africa during Apartheid and South Africa since 1994. The new South African Constitution also has a unique emphasis on social rights, reflecting the historical context of uneven access to resources on the basis of race.

Strong (1980) also illustrates what appears to be one of the assumptions about rights - that they are in some way fundamental to ‘being human’. It is critical that the capacity to exercise one’s rights is tied to an understanding of what it means to be human. For those in vulnerable positions in society, there may be several barriers to the assertion of rights. The move to social rights is a recognition that not all people in a society have an equal capacity to exert their rights, and consequently there is in, some sense, a duty on those in more powerful positions to enhance this capacity. What an exploration of rights in the context of mental illness may in fact reveal is that the barriers to asserting one’s rights are complex, involving intra-psychic, interpersonal and social factors.

Freedén’s (1991) definition, quoted at the beginning of this section, introduces the idea that

rights require action on the part of others for their protection. Wellman (1997) suggests that rights are claims for entitlement, in the sense that a person with a right is entitled to act in a certain way, or be treated in a certain way by others. And Strong (1980) seems to illustrate the idea that to have rights is in some way fundamental to being human. Freedman's definition also makes mention of certain attributes which deserve protection. What seems to come through in these ideas is the sense that rights are in some way linked to an idea of worth. Certain aspects of being human are deemed worthy of protection, and to be entitled is to be worthy. This would seem an area in which a psychological exploration of rights might open up new understandings and perspectives. For example, questions arise as to the subjective dimensions of rights, such as what it means to be a rights-bearer and what exactly it is that influences a person's subjective understanding of their entitlement to rights.

It seems clear that understandings of human rights evolve, and are therefore continuously debated, as evidenced by the number of legal philosophers devoting attention to this field (see for example Wellman, 1997; Dworkin, 1977). In the legal field, the way rights are understood and applied is constantly shaped by judicial review and court rulings. This suggests that rights are socially agreed upon, because as society changes, so its conceptualisation of human rights will change. However, this presents a paradox. Rights, particularly human rights, are "those moral rights which are owed to each man or woman solely by reason of being human" (MacFarlane, 1985, p. 3). Many writers on the subject of human rights (e.g., Freedman, 1991; MacFarlane, 1985; Wellman, 1997) assume that human rights are characterised by their universality i.e. their application across cultures and contexts because they pertain to all human beings.

Yet Bobbio (1996) asserts that there can be no fundamental principle for human rights owing

to the historical relativism of rights, and the fact that any attempt at defining human rights invariably involves an appeal to values. This necessitates an argument between values, and therefore invites the argument for relativism, i.e. as different notions come to be more or less valued by society, the definition of the content of rights will change. This also suggests that different interests seek different benefits from the human rights framework, emphasising certain aspects over others. For example, property rights were a central concern for eighteenth century landowners (Glendon, 1991), and shaped much of the debate around rights, but more recently, the debate has shifted to social and economic rights (Bobbio, 1996), reflecting other interests. It also seems that human rights, in our current conception of them, are relatively new (Glendon, 1991). However, as Glendon (1991) points out, human rights are applied differently and understood differently in different contexts, cultures and countries. This debate suggests that human rights are socially constructed. Milne (1986) points out that our idea of rights is only one possible construction. He suggests that the dominant conception of human rights “ignores not only cultural diversity but also the social basis of personal identity” (Milne, 1986, p. 5). The reference to the “social basis of personal identity” suggests that issues of identity are important for the development of an understanding of rights, and the influence of social factors on that identity. Questions arise as to the way personal identity affects the capacity to assert one’s rights, as well as how rights are understood. The individual orientation of rights also suggests that the identity of the individuals concerned is relevant for the understanding of rights in any one context. The idea of a “social basis” (ibid.) at the same time implies that a person’s experiences as a member of society will affect his/her understanding of their rights.

There is some debate over the distinction between moral and legal rights (Wellman, 1997). This debate stems from the belief that the protection afforded by the legal system is the best

guarantee against an abuse of rights (Bobbio, 1996). As soon as the legal system defines rights, through the enactment of a Constitution or a Bill of Rights and upholding the rights described therein, it is argued that these rights become positive or legal rights. However, the counter-argument is that moral rights are not always protected by law, but have an authority based, in some sense, on a social agreement of morality. It thus becomes possible for individuals to make claims that their rights have been abused, and seek recourse to action, even though such rights may not be recognised by the laws of their own country. (Bobbio, 1996). For example, the UN Universal Declaration of Human Rights differs from the South African Bill of Rights, and the rights charters of various other countries. It is possible for individuals in a certain country to appeal for international protection for a perceived abuse of their rights, for example by their government. The justification for intervention is based on a perceived moral imperative, rather than a codified legal one. This suggests that human rights are intimately linked to a socially agreed upon morality. Wellman (1997) suggests that legal rights are defined by “authoritative legal sources, especially statutes and opinions of appellate court” yet there “are no authoritative moral sources”(p. 14). Despite the fact that moral rights come to have credibility through the process of social negotiation, once they are defined, legal rights tend to have a more authoritative capacity. They are set down in law, where moral rights are, in some sense, always debatable.

Another important distinction is the degree to which each of these rights relies on society for their enforcement. Legal rights function to an extent in a context that is isolated from society. While the ‘will’ of society, and appeals to what constitutes ‘the good of society’, impact on the judicial application of legal rights, the courts have the capacity to impose concrete penalties on those deemed to be guilty of violating legal rights. This occurs to an extent in the context of a social institution governed by certain rules which, once formalised, take on an

existence of their own, i.e. not requiring continuous ongoing input from society. It is the court, not some abstract conception of 'society', which then becomes responsible for sanctioning a violation of rights.

In contrast to legal rights, moral rights are socially protected. Wellman (1997) suggests that all rights are socially protected and says this conceptualisation is fairly unproblematic, in the sense that most theorists on rights have made similar claims. He goes further, saying that, "only if the force of society actually did, or ought to, protect a right could rights function to prevent or resolve conflicts between the individual members of society" (p. 5). He adds that failure to protect a right undermines its "moral significance" (*ibid.*), suggesting that the right is not valued by society. Bobbio makes an argument against this understanding of rights. He says that the internationalisation of human rights has weakened the effectiveness of the human rights doctrine because there is no international method of punishment aside from "moral censure" (Bobbio, 1996, p. 49). He argues that in the absence of a legal system with the power to administer punishment for rights violations, there is little impetus to act in accordance with human rights as defined in international declarations such as the UN International Declaration on Human Rights. This suggests that rights will only be implemented in the presence of a legal system. If rights can be protected by social sanctions, and are linked to a social agreement of morality, rights may be thought to work on a social level, influencing the way people interact with one another, or ideas about how people ought to interact. Having a knowledge of one's rights may be used as a basis to challenge people who are acting in a manner contrary to these rights.

It seems rights are held to be universal, because they apply to all people, "solely by reason of being human" (MacFarlane, 1985, p. 3). Yet at the same time, rights evolve over time, are

codified in different ways and may be debated. This suggests that rights are in fact socially constructed. This implies a form of social agreement, while notions of rights remain fluid. Rights are however cast as 'moral', which lends urgency to their protection. However, the socially constructed nature of rights also implies the potential for rights to function as a means of legitimising a particular world-view, that of those with the power to define what rights are. It consequently becomes important to look at the meaning the 'rights discourse' has for those in less powerful positions in society.

Another aspect of rights that is relevant is suggested by an understanding of rights as essentially a claim an *individual* can make against a group. Rights have historically been conceptualised as offering protection to individuals from society, particularly the State (Lykes, 1996). This implies a need to investigate what rights mean to individuals and how they are understood. It also implies that what is needed is an understanding of the factors which influence an individual's capacity to assert his/her rights. Rights represent a claim to entitlement (Wellman, 1997), which suggests that the individual would need to feel entitled to what is being claimed, before any claim is made.

Rights are also intimately linked with issues of identity. For example, the existence of categories of rights, such as the rights of people with disabilities suggests that, in discussing the rights of a group, that particular group identity is being made salient for the individual at that time. Asserting one's rights involves a claim for entitlement. As such, a sense of one's identity would also seem to be invoked in the act of claiming one's rights, because the individual is asserting that they should be treated in a manner which conforms to their sense of themselves. Consequently, rights issues are related to issues of identity and self-perception.

Rights seem to be both legal and social objects, being enforceable both through the law and through, “cultural sanctions” (Drewett, 1999, p 120). Yet the psychological focus of this research draws attention to the social dimensions of rights. Working with those diagnosed with mental illness suggests the need to examine what is involved in being an individual diagnosed with mental illness in society. The aim of this is to understand some of the issues which might influence the way rights are made use of, as well as the way they function to protect the ‘vulnerable’. Although much of the literature focuses on the legal aspects of rights, it is clear that there is an essential psychological component involved in making these legal systems work. This psychological aspect constitutes the focus of this study.

Mental Illness and Human Rights

With these general comments on human rights, it is now possible to move on to examinations of the rights of people diagnosed with mental illness, in order to get some sense of what points of contention there are relating to their rights. Much of what has been written on this issue has been done by psychiatrists and other ‘experts’ in this field. It would seem useful to compare this with what emerges as the interests of those diagnosed with mental illness.

Those diagnosed with mental illness seem a valid subject for study on the basis of the way society has responded to them historically. The overwhelming conclusion that can be reached from even the most cursory examination of the history of treatment for mental illness in Western society is that those considered mentally ill, or ‘mad’ in earlier times, are dealt with harshly. I focus on Western history because it is this tradition which has dominated South African psychiatry (Swartz, 1996) and which still continues to shape mental health care. The focus on treatment of the mentally ill by society, whether it be in a social context or in an

institutional context is relevant for a study of rights given that rights deal with the way the individual interacts with society, offering a protection for him/her from others.

The History of Mental Health Care

The history of mental illness is a history of people shunned by society, either through being cast out of their homes or, later, incarcerated in asylums (Shorter, 1997). The asylums, dating from medieval times, initially were not places for treatment, but served a custodial purpose (ibid.). Pinel is famously attributed with freeing the 'lunatics', breaking their chains and ushering in a more humanitarian approach to the 'afflicted'. Although this is somewhat debatable (Foucault, 1967), what is clear is that there was a move towards therapeutic care from around the late eighteenth century (Shorter, 1997). However, even this resulted in only marginally better treatment for those incarcerated (Foucault, 1967). Such treatment today would undoubtedly be cast as a violation of human rights.

Methods of treatment developed over time, yet there seems to be something of a common theme of incarceration, until the advent of deinstitutionalisation. What is also clear is that psychiatry has tended to focus on mental illness as biologically-based, giving rise to treatments that focussed on the body. This view makes it possible for Isaac and Armat to claim that the, "major mental illnesses...are diseases of the brain. A series of scientific breakthroughs...has established this beyond serious question" (Isaac & Armat, 1990, p. 19). Patient's responses to some of these treatments suggest that at times they are viewed as a form of punishment (see Isaac & Armat, 1990). These ideas, of treatment as punishment and the debate about the justification for incarceration continue to dominate the discussions about the rights of those diagnosed with mental illness (Ussher, 1991).

Current Thinking on the Rights of the Mentally Ill

Care for people with mental illness has been characterised by one feature in particular over the last fifty years. This has been the move from care in large institutions to care in the community - the move towards 'deinstitutionalisation.' One of the key motivations behind this move has been the concept of the rights of the 'patient' (Bachrach, 1997). Institutional care for long periods was felt to violate the mental health service users' rights to freedom and autonomy. From this broad concern, there has been ongoing debate in the field to try and identify what exactly are the rights of the mental health service user, and how his/her rights intersect with the rights of other people. It is this area which has been the focus of most research. There are a variety of concerns under this broad topic, including involuntary care (Brown & Rayne, 1989; Devereux, 1994; Kapp, 1994; McLachlan & Mulder, 1999), the right to care (Hayes, Boerma & Ovadia, 1994; Legemaate, 1988) and the negotiation between the rights of the mental health service user and the community (Hayes, Boerma & Ovadia, 1994; Reda, 1996). This is by no means an exhaustive review, but is meant to give an idea of the field. The value of this exercise is that it gives some understanding of how those in the field understand and conceive the rights of those diagnosed with mental illness. These conceptions may in fact differ from the conceptions of those who experience mental illness directly and who are meant to claim these rights. Understanding these issues also provides a framework within which one can contextualise the rights contained in the 2001 Mental Health Care Bill (see Appendix).

In terms of rights and the mentally ill, most of the literature available deals with the rights of the mentally ill person in connection with institutions. This is somewhat problematic given the move to care in the community, which suggests that a person's rights once released from the institution and living in the community should be examined. Various rights come into

play in connection with the institution. One of the key debates relates to the interaction between the rights of the mentally ill person to their liberty and the right of the community and its members to be protected from harm. This finds its expression in debates around defensive psychiatry (Brown and Rayne, 1989). Related to this is the debate between the right to liberty or freedom of movement, as encapsulated in what has been called the right to autonomy by various authors (Gendreau, 1997; Legemaate, 1988; McLachlan and Mulder, 1999) and the right to healthcare. What also emerges from the literature is support for the idea that the way rights are applied varies (Brown & Smith, 1988) depending on the context, challenging the idea that rights are universally understood and applied.

Kapp (1994), in tracing rights to treatment as well as the rights to refuse treatment in American case law, suggests that the right to refuse treatment often does not enjoy much judicial support. "The vast majority of cases result in the patient's objection being over-ruled and the treatment eventually permitted" (Kapp, 1994, p. 230). Indeed, many psychiatrists object to using this procedure at all, saying that it can result in delays in the provision of treatment which are harmful to the patient, "(preventing) them (the psychiatrists) from fulfilling their moral responsibility to treat patients whose rationality has been impaired by illness" (Miller, 1991, p. 267). Thus, in a very real sense, there is a question about whether these rights will move from the realm of "paper rights" (Wellman, 1997, p 5). "(Real) rights are those recognised and enforced by the courts, while those written into legal sources but left unprotected by society are merely paper rights" (ibid.). Gendreau explains the situation thus: "(There is a) traditional psychiatric presumption that the acceptance of a treatment is, by definition, reasonable and healthy and that a refusal of a treatment is not only presumed unreasonable but also a symptom of mental illness"(Gendreau, 1997, p. 276). This suggests the tendency on the part of the medical profession to invalidate what may be genuine

concerns on the part of those diagnosed with mental illness. If this tendency exists, a question arises as to the effect this will have on the person's confidence to assert their rights. In particular, if a person feels that their objection is unlikely to be upheld, will that person be likely to stand up for his/her rights?

Kapp (1994) drew attention to the way the issues involved in the right to treatment and the right to refuse treatment centre on decisions regarding "the criteria to find a person incompetent to make personal decisions" (p. 230). Kapp highlights the fact that these criteria are not the same as those regarding involuntary hospitalisation. Specifically, the right to treatment includes the right to receive the treatment that the patient chooses and a decision as to whether or not the patient is capable of making this decision. This right has been debated because of the financial expense involved as well as the question of whether "judicial/legislative...mandates for treatment (are) inherently incapable of assuring real quality of care"(ibid.). This second issue cuts to the heart of the issue of patient's rights. That is, there is a question over whether legal protections are an effective means of controlling what happens between a doctor and his/her patient. The issue of refusal of treatment is also problematic since this refusal "may be a rational reflection of the patient's personal risk-to-benefit analysis"(ibid.). Kapp suggests that the way these rights are implemented depends "more on the basis of pragmatic imperatives...than of clinical diagnosis or legal theory" (ibid.).

Brown and Rayne (1989) draw attention to the ways in which a patient's rights may be secondary to the psychiatrist's desire to avoid litigation from members of the community, or family members, which they term, "defensive psychiatry" (p. 534). The issue of defensive psychiatry reveals the paradox that people diagnosed with a mental illness, "are viewed as

too incapacitated and dangerous to be free, but not too incapacitated to be expected to instigate the legal safeguards to which they are entitled” (Brown & Rayne, 1989, p. 540), i.e. to seek the legal protection which they enjoy under legislation on patient’s rights. This paradox persists, for example, in the draft Mental Health Care Bill (2001) in South Africa. This makes provision for the mental health care user to appeal against the decision to have him/her involuntarily committed within thirty days (Mental Health Care Bill, Section 35.1). It also allows the spouse, or another relative, to appeal against the decision. However, members of the family are the most likely candidates to have the person admitted, as they have the power to make this request. So, it seems that the mental health care user is likely to be the one who will have to make such an appeal. Kapp (1994) suggests that few such appeals against treatment by service users are successful. These experiences provide the historical background that accompanies the person diagnosed with a mental illness into the community.

What seems clear from a reading of the literature on the rights of those with mental illness is that the focus is on rights as they relate to treatment, particularly treatment in the institution. Yet the advent of deinstitutionalisation means that large numbers of people diagnosed with mental illness are likely to be living in the community. The objective of deinstitutionalisation is that people should live their lives with minimal ‘interference’ from the mental health system. This implies that there should be an attempt to maintain work, family and social interactions. This also implies that the issue of rights is likely to become salient in these contexts. Yet there is little in the literature to suggest that such a connection has been examined in any meaningful way, and this is an issue which needs to be addressed. At a fundamental level, the issue of the role rights play in ‘ordinary life’ such as in employment situations as well as family and social interactions should also be investigated, along with rights as they pertain to the institution and treatment. It must be emphasised that issues of

treatment are likely to remain a concern for those diagnosed with mental illness living in the community, because, in most cases, they will continue to receive treatment and medication in the community. It is this more 'holistic' approach to rights that this study assumes as a point of departure.

South Africa and Rights for Those Diagnosed as Mentally Ill

In South Africa, there has been a long history of abuse of human rights in all spheres of life. A review of institutions in South Africa, published in 1998, suggest that "there is an inadequate recognition in law and in the culture that people with mental health problems or mental retardation have human rights" (American Association for the Advancement of Science, 1998, p. 98). This was coupled with reports of abuse in institutions, involuntary sterilisation of people with mental retardation, the persistent dominance of the institutional model of care and the continuing effects of a racial bias in the provision of services which has meant that the best services continue to be found in previously white areas, a legacy of Apartheid. Foster (1990) describes the period after 1948 as being one "characterised by the systematic extension of racism into all aspects of mental health" (p. 55) and it is the effects of this that are still evident today. Foster also recognises the fact that new developments in mental health care "lagged behind by decades" (ibid.). The democratically elected government has taken steps to address the issue of human rights in all spheres of South African life, as evident in the Bill of Rights. There have also been substantial moves to bring South Africa in line with the international moves towards community care. Yet there remain ongoing debates about the quality of care and the potential for abuses that exist in the mental healthcare system (See Swartz and MacGregor, 2000; Dartnall, Madiba, Porteus and Lee, 1999).

What is also relevant in the South African context is the possibility of “multiple layers of oppression which frame” the experience of people diagnosed with mental illnesses (Bernard, 1999, p. 327). South Africa has a history of racial oppression, which extended into the provision of health services (Foster, 1990). The social context of racism within South African society is likely to be a factor in the experience of black people diagnosed with mental illness. Similarly, the issues of class, in the context of persistent disparities in income, and gender play a role in shaping the experience of rights for people diagnosed with mental illness. “Marginalisation is the quintessential experience of black and disabled people” (Stuart, 1992, p. 178). Any investigation into the understandings of human rights in relation to people with mental illnesses must remain cognisant of the intersections of these various factors, which impact both on the identity of someone diagnosed with a mental illness, and their experiences. These experiences must be looked at within the context of the mental health system, and in the context of living in the community. South Africa remains characterised by vastly different experiences based on race, gender and class divides. This is likely to add complexity to any discussion on rights.

The issue of mental illness in the South African context is also itself complicated by issues related to certain cultural practices which affect the interaction between people diagnosed with mental illnesses and their communities. It is not just the psychiatric system that engages with the issue of the diagnosis and treatment of mental illness in South Africa. Faith healers and indigenous healers also fulfil this function for large parts of the population (Swartz, 1998). The issue is further complicated by arguments for and against the existence of ‘culture-bound’ syndromes (for a more detailed discussion see Sodi, 1998; Swartz, 1986; Swartz, 1987; Swartz, 1998). These ideas rest on particular world-views, which shape the explanations given for the experience. These world-views are likely to continue to play a role

in the experience of the person diagnosed with a mental illness while he/she is living in a traditional community. These issues are also likely to exert an influence on how someone diagnosed with a mental illness will understand and make use of his/her rights.

While Robertson, Zwi, Ensink *et al* (1997) recognise that the rights of all people, including those diagnosed with mental illness, are protected by the South African Constitution, they recommend the adoption of a “specific charter” (p. 91) applying to people with mental illness. This process is nearing completion now, with the Mental Health Care Bill in the final stages of the legislative process at the time of writing. Human rights are “the essence and the objective” of the new bill (Freeman, 2001, para. 1). The new bill takes heed of the suggestions by Robertson, Zwi, Ensink *et al* (1997) that conditions for admission be reviewed, the observation period for court referred patients be reduced, the procedure for the incarceration of State patients be revised and also that the length of time between periodical reports be reduced.

Although there have been recent attempts to establish the rights of people diagnosed with mental illness, there are difficulties in actualising these. The mentally ill person faces two distinct problems in this regard. The first is that, quite simply, they may be too ill to assert their rights or to make decisions, for example with regard to treatment. The second problem is linked to Foucault’s idea that “Liberty is a *practice*...it can never be inherent in the structure of things to guarantee the exercise of freedom” (Foucault, 1991, p. 245). The institutions and the mental health structures continue to operate in a context of significant power differentials between staff and service users. It is possible that a person who has at some stage ‘lost their mind’ will not be regarded as capable of sound judgements at later stages. This seems to come through in Kapp’s (1994) findings that, despite any objections on

the part of the patient, a review panel usually upholds the clinician's decision regarding treatment. There are questions over how well schooled someone diagnosed with a mental illness will be in the practice of their rights. Doubts arise as to whether they will feel competent enough to assert their rights in the face of so many other 'rational' people telling them that they know what is best for them. Alternatively, they may feel that they do know what their rights are and do feel that they have been violated, but do not know how to rectify the situation or feel that this is a fruitless task because no-one will really listen to them.

This thus represents a double-bind for the mentally ill. They have Constitutional and legal guarantees of their rights. They may also have forums for expressing their discontent at the way they are being dealt with. But the fact that their rationality is also a matter of debate may make them vulnerable to being dismissed as paranoid, obsessive, etc. due to the nature of their illness. The individualistic orientation of rights places the responsibility for asserting those rights squarely at the feet of the mentally ill. So people diagnosed with mental illness are responsible for protecting their own rights, they have that guarantee as equal to all other members of society. Yet they may not have an equal capacity to assert their rights, either due to illness or a lack of confidence due to the internalisation of contextual factors. Unfortunately they may also bear the responsibility for that failure - they are supposed to have the same structural privileges as any other member of society. In this way, rights legislation may run the risk of being disabling rather than enabling for people diagnosed with mental illness.

The review of the literature suggests that the rights of people diagnosed with mental illness have most commonly been examined in the context of institutionalisation and treatment. However, the move towards community care means that the institution is likely to play less

of a role in the lives of people diagnosed with mental illness, since less of their time is likely to be spent inside an institution. It is perhaps ironic that, due to the historic focus on the institution, outside the institution the mentally ill may in fact be less protected than inside it. This suggests the need to examine rights as they occur in the community and the social context. Furthermore, rights operate in a social context, which suggests the need to examine that context in order to understand how it impacts on the ability of people diagnosed with mental illness to claim their rights.

There is evidence of widespread discrimination against those defined as mentally ill. In exploring the notion of the capacity to assert their rights, it becomes necessary both to explore some of the features of the discrimination, and the ways in which this impacts on the self-concept of the person diagnosed with a mental illness. Attention must also be given to the ways in which the experiences of people diagnosed with mental illnesses are shaped by their experiences as people positioned due to a range of different factors, such as class, race and gender. The institution also needs to be examined because experiences within the mental health system play a role in shaping expectations and perceptions once released. The person's experiences as someone diagnosed with a mental illness yet living in the community are also likely to have an impact on the meaning that rights have for them, and their interests in this matter. The influence of these issues on the lives of those diagnosed with mental illness and the ways in which they impact on understandings of human rights will be dealt with in the next chapter.

Chapter 3

Theoretical Orientation II: The Social Psychological Dimensions of Rights

The preceding section highlighted the idea that identity plays a role in understanding rights. Rights can never be divorced from the social context in which they operate, because they are concerned with individuals, and speak to everyday interactions between people. This section deals with some ways of conceptualising the person diagnosed with a mental illness as a 'rights-bearer', which suggests that some understanding of identity is necessary. This also seems relevant given that one's experience and identity influence how rights come to be constructed by an individual. Some of the issues in this regard will be highlighted.

Mental Illness as Disability

The issues faced by those diagnosed with mental illnesses are similar in many respects to the issues faced by people with disabilities. Mental illness is often mentioned in the same framework as disability, as one type of impairment (see for example Finkelstein, 1993). Thus it would seem that those diagnosed with mental illnesses constitute a sub-group under the umbrella categorisation of 'disabled'. However, there has been little work done to investigate the ways in which mental illness is related to other disabilities. Some of these ideas would seem relevant to an understanding of the position of people diagnosed as mentally ill, and the factors which influence their position. Yet, at the same time it is necessary to remain cognisant of the differences between mental illness and other forms of impairment, in order to avoid the danger of ignoring the realities of the impairment (French, 1993). For this reason, I begin with an examination of some of the differences between mental illness and other forms of impairment.

The first distinction to be made is between physical impairments and mental impairments. Mental illness and mental retardation are subject to different practices, and the methods of exclusion related to those diagnosed with mental and physical impairments are different. Ensuring that buildings are accessible to wheelchairs is unlikely to be one of the primary concerns of someone defined as mentally retarded, or rather any more than it should be a concern for everyone. The exclusions that people with mental impairments are subject to are less likely to focus on the physical environment. There is also likely to be a distinction within the grouping of mental disabilities between those who have a mental handicap and those who are diagnosed with a mental illness. This distinction today relates to different institutional practices that those in each group will experience. As an example, the draft Mental Health Care Bill (2001) identifies different institutions and health establishments to deal with mental retardation and mental illness.

Perhaps the major factor which serves to make mental illness unique is the fact that it does not affect people in the same way at all times, but instead moves between different degrees of impairment. For example, during a psychotic episode, a person may exhibit bizarre behaviour, and have difficulty being understood when speaking to others. But at other times, there may be little to differentiate them from anyone else. The advent of psychiatric medications, which have some success in controlling symptoms, also contributes to this situation. However, a person in a wheelchair has a very visible reminder to others that they have an impairment. Similarly, while someone who has a visual impairment may not initially appear different, they will not be able to read a menu in a restaurant unless it is written in Braille. These two examples draw attention to two issues involved in having an impairment, the way others treat the individual concerned and the ability the individual has to fulfil certain functions. It is important to note that this emphasis on functionality is a particular

feature of the experience of disability in the modern industrial age, where Capitalism's emphasis on the marketability of one's labour power makes obstructions to productivity a relevant concern (Oliver, 1990).

Mental illness would seem unique among the impairments which are associated with disabilities because (a) it is not visible to others and, (b) unlike mental retardation, it would not seem to affect the individual's ability to accomplish certain tasks at all times in the same way. The question arises as to how this fluctuating level of impairment impacts on people diagnosed with a mental illness, in particular, the impact this has on their sense of their own capabilities and whether or not this sense of themselves resonates with other people's expectations of them. It is possible that their identity, their sense of themselves is not the same as other people's ideas of them and their capabilities.

Despite the differences between mental illness and other forms of disability, it may be possible that some of the issues faced by those diagnosed with a mental illness might be better understood with the aid of work conducted in the field of disability studies. Of particular relevance for a discussion of rights is the distinction between what Oliver has termed the social model of disability and the personal tragedy theory (Oliver, 1990). In his social model of disability, Oliver makes an argument for a shift in focus to the ways in which the social environment and the organisation of society disable people, rather than the disability residing within the individual. This approach emphasises the significance of the way in which other people treat the person with an impairment. From this position, the experience of disability itself is fundamentally moulded through social interactions. While Oliver does not focus on the subject of rights specifically, these ideas open up the possibility that someone with an impairment may have many aspects of their experience mediated

through the eyes of others. If someone diagnosed with a mental illness accepts others' interpretation of their experience, rights may go unclaimed due to their own diminished perceptions of their own abilities.

Oliver's social model builds on an understanding of the differences between disability and impairment (Oliver, 1990). Disability is explained as the, "disadvantage or restriction of activity caused by contemporary social organisation" (UPIAS, cited in Oliver, 1990, p. 11). This contrasts with impairment that is the 'actual' illness or diminished function of the disabled person. Closely linked to this idea is what Oliver terms the "personal tragedy theory" (Oliver, 1990, p. 1). This, as the name implies, is a belief that what has 'happened to' the person concerned is a tragic personal affliction. The medical fraternity has played a significant role in promoting the growth of such a view. The medical approach emphasises impairment as a problem requiring a solution, or cure (Abberley, 1996). This orientation focuses on the individual in need of 'repair' in order to make him/her as productive as possible. This suggests that there are materialist concerns involved (Barnes, 1996).

The power of the medical enterprise over the field of disability has been criticised by disability rights theorists and students of mental health (Szasz, 1972; Oliver, 1990). Foucault has traced the origins of the particular power of the medical establishment in modern life to developments in the eighteenth and nineteenth century. Particularly, he makes an argument for the role the "medical gaze" (Foucault, 1980, p. 146) has played in 'individualising' the issue of power. The 'individualising tendency' can be seen as a feature of capitalist societies. The individual becomes an object of study only when their labour power becomes a commodity. This process was linked to industrialisation, and the move away from feudalism. In the feudal system, there is no need to monitor the productivity of individuals in any real

way, because the family is the major form of work unit (Abberley, 1996). However, with people moving off the land into cities, the individual is forced to sell their labour, and acquire skills and training to make themselves more 'marketable'. In such a situation it has been argued that the impaired individual is less marketable and less productive, which encouraged the marginalisation of people with impairments. (See Barnes, 1996; Oliver, 1990) The development of medical technologies has been linked to an attempt to make the work force more productive, by making each individual as productive as possible, by minimising the effect of the impairment.

The effect of a belief in medical technology as the 'answer' to the 'problem' of disability, is that impairment and disability become conflated and the environmental factors (including the social environment) which contribute to the disablement of the person, are ignored. Effectively, this places the responsibility for overcoming the 'tragedy' squarely on the shoulders of the impaired individual (Oliver, 1990). In terms of physical disability, this is perhaps easier to conceptualise, where access to buildings for someone using a wheelchair may be restricted by the absence of ramps or a visually-impaired person may not be able to work in an office because of their inability to read hand-written memoranda. These are problems in the way society is organised; yet the standard view is to accept that the exclusion flows from the impairment, and is therefore in some way 'natural' (ibid.).

This idea can be linked to Foucault's sense that the individual must regulate and monitor themselves. Not only must an individual make themselves marketable, they must ensure that they fulfil their obligations by taking part in certain institutionalised practices. Foucault uses the eighteenth century idea of a Panopticon to convey this (Foucault, 1980). The Panopticon is a prison in which the cells are made of glass, arranged in a circle around a central

watchtower. It is impossible for prisoners to see into the watchtower. Thus, they have the sense that they *could* be being watched at any time. Consequently, they feel obliged to conform to the rules of the prison and refrain from illegal activities. Foucault suggests that this idea informed much of the architecture of institutions of the time, subjecting the inmates (including the mentally ill, prisoners, patients, workers and schoolboys - Foucault, 1980) to constant surveillance. Foucault describes this as "immersing people in a field of total visibility where the opinion, observation and discourse of others would restrain them from harmful acts." (1980, p. 157). Gradually, he suggests that the Panopticon has been internalised as part of a process influenced by various institutional practices. Consequently, in modern society people monitor and regulate themselves, to ensure that they conform to the requirements defined by society's institutions. The effect on those with impairments was to 'individualise' their handicap. In contrast, the social model of disability encourages an engagement with the ways in which society handicaps impaired individuals.

People diagnosed with mental illness are marginalised within society (Barnham & Hayward, 1995). Using the above argument, it is possible that their exclusion exceeds the impact of their impairment. Where it becomes possible to envision social situations in which the handicap could be minimised, it implies that the disabled person's reduced participation in society is not 'natural' but rather the result of the prevailing social structure. For example, it is possible to imagine a situation in which people diagnosed with a mental illness could be employed. However, this would in many cases entail an alteration of the existing arrangement between employer and employee, to allow for the fact that at times a person diagnosed with a mental illness is more able to work than others (Edwards, 2000). It now becomes a matter of economics and attitude (of employers, etc.) as to whether that person is employed or not. This is the particular value which the social model of disability brings to a

study of people diagnosed with a mental illness, highlighting the ostensibly political nature of what might on the surface seem 'natural' arrangements (Oliver, 1990). The suggestion is that the environment creates the disability in a sense, rather than the disability flowing as an inevitable consequence of having an impairment. In the field of mental illness, it might be the case that participants' experiences resonate with these ideas, feeling themselves marginalised in ways that exceed the effect of their impairment. It would seem necessary to investigate some of the possibilities the social model opens up for understanding rights. In particular, the individualistic approach to disability may have the effect of casting certain ideas as natural, and therefore not framed as 'rights issues'. Conversely, the nature of their exclusion may turn out to have a significant impact on the conception of rights that emerges from the discussions.

If part of the disability stems from the organisation of society, this means that people diagnosed with mental illnesses are struggling not only to overcome their own impairment but also the organisation of society. This situation sets the impaired person up for failure, because of the near impossibility of overcoming the myriad exclusions which society has established. The personal tragedy theory suggests that this reinforces a sense of responsibility for this failure, a factor likely to increase feelings of inadequacy. To the extent that this is true, there may be the possibility that the impaired individual does not feel confident to keep on perpetually trying to overcome a system so heavily stacked against him/her, and resigns him/herself to the exclusion. This could in some sense account for the finding that those diagnosed with a mental illness, for example, suffer from low self-esteem (Wright, Gronfein and Owen, 2000). It seems possible that a diminished sense of self-worth will have implications for the idea that rights reflect a claim to entitlement. It may be the case that rights go unclaimed as a consequence of a feeling that the individual is not entitled to make

the particular claim. Asserting one's rights implies an inherent rejection of the dis-empowering status quo.

While re-framing the debate (to take into account the impact of social organisation) is desirable, care must be taken not to dismiss the effect of the impairment on an individual. French (1993) points out that, if the disability is social, "social manipulation" suggests itself as the solution (p. 17). However, she points out that some of these situations are impossible to solve in this way. She argues for a more in-depth look at the complexities involved in having an impairment (See also Abberley, 1996, Barnes, 1996). Ignoring the effects of impairment could in a sense serve to isolate people from the experience of being impaired, and deny them the emotions associated with such an experience. There are practical realities associated with having an impairment as well, and these, while they may be diminished, cannot be ignored or totally eradicated.

The discussion of the social model draws attention to the ways in which people with impairments are excluded from society in ways which go far beyond whatever limitations they may experience as a consequence of their impairments, if any. This suggests that various features of social organisation cause the exclusion. Writers in the field of disability studies (Oliver, 1990) also make the claim that the institutionalised practices of various disciplines, such as medicine, serve to position people with impairments in a certain way. This position emphasises functionality as a 'natural' objective for those with impairments, individualising the disability and making the exclusion seem a natural consequence of the impairment. Rights represent a challenge to various forms of exclusion experienced by people with impairments. Yet the social model of disability suggests that one possible danger is that certain exclusions may appear 'natural' and consequently not be seen to fall within the reach

of the law. This also relates to who has the power to set the 'rights-agenda', given the social exclusion of people with mental illnesses. This research sets out to explore the meaning that rights have for people diagnosed with mental illnesses and the ways in which their experiences impact on their understanding of rights. The possibility that their understanding of rights may differ from the dominant views on rights for those diagnosed with mental illness is likely to have implications for the application of rights in this field.

In the way that rights are generally conceived, it is an individual who claims rights. Yet, it may be the case that the individualistic orientation towards disability, which is currently dominant, may serve to increase feelings of self-blame among those with impairments. To the extent that this is true, the possibility exists that rights will go unclaimed. Rights are individualistic in emphasis. In the absence of an examination of both the social barriers to claiming rights, and the intra-psychic barriers to asserting one's rights, it is possible that rights could serve to dis-empower, rather than empower people with impairments, because if their rights are not claimed, the blame rests squarely with them.

The Social Construction of Mental Illness

The issue of rights has been examined in terms of the way institutional practices influence the claiming of rights. Institutional practices are also social practices, influencing the ways in which society as a whole responds to people with impairments of all kinds. As with rights, these practices are influenced by social factors, such as the discourse surrounding mental illness. Foucault suggests that discourse was a constitutive force, becoming embodied in institutions and institutional practices as well as influencing the organisation of society. Discourses are pervasive, operating at various levels (Foucault, 1972: 1976). At this point, an examination of the ways in which various ideas shape our understanding of mental illness

seems necessary. This has relevance for a discussion of rights because those diagnosed with a mental illness are subject to the same discursive constructions of mental illness. If these negative understandings of persons diagnosed with mental illness are pervasive in society, it is possible that this will impact on the self-image of those who are diagnosed with mental illness. This may consequently have a negative impact on their confidence and hence their capacity to claim their rights.

In the case of mental illness, it is not only the disability that is socially constructed. The impairment itself has been argued to be a product of social relations, an idea which partly inspired the anti-psychiatry movement, led by writers such as Szasz (1972) and Laing (1965). This is due in part to the peculiar power medical practitioners have in determining and describing mental illness. It is this which has led Szasz (1972) to declare that mental illness is in actual fact a myth. He argues that, far from being an actual illness in the physical sense, what we term mental illnesses are more particularly disorders of speech.

Even if one is not to take such a radical view, the fact that it is possible for the American Psychiatric Association to review its Diagnostic and Statistical Manual, and put contentious issues to a vote suggests that notions of mental illness are not static concepts, and evolve through debate. "When final decisions are made about DSM-IV, they will be based primarily on *expert consensus*, rather than on data" (Spitzer, 1991, p. 294, my emphasis). This calls into question the assertion that mental illness has the same 'objective' reality as physical illness. The issue of power becomes relevant, since there is an assumption that the 'expert' should be given the power to make such decisions. The expert in this instance is undoubtedly a member of the psychiatry fraternity, and not someone with a mental illness. Again there is the idea that the psychiatrist has a considerable amount of power at his/her

command. It is the process of debate and consensus that allows the 'discovery' of new illnesses.

As Szasz (1993) points out, there is no laboratory test for mental illness. The symptoms vary to a significant degree for a single diagnosis, and symptoms are shared by different diagnoses. The fact that one person may be given different diagnoses at different stages bears testimony to the particular complexities of mental illness. If the nature of mental illness (the actual impairment) is subject to debate, how does this affect the debate on what constitutes impairment and what constitutes the disability associated with the prevailing social conditions? For example, one theory advanced by Seligman is that depression results from 'learned helplessness' (Seligman, 1975). However, it would seem exceedingly difficult to untangle the feelings of helplessness that are the result of the depression (the impairment) from the helplessness which flows from the disabling environment, in which people have diminished expectations of the depressed person and 'do too much' for the depressed person (Edwards, 2000). In such a context, there is questionable value in pathologising this sense of helplessness.

It is important at this point to examine how the person with a mental illness has been thought of, i.e. discursively constructed. There is a particular value in adopting a historical approach here. This is because it allows insight into the way the discourse which has developed around mental illness and madness has developed. Foucault draws attention to the origins of discourses (Foucault, 1972: 1976), and an understanding of the power of discourse is relevant because it allows insight into the factors which have shaped and continue to shape understandings of any given subject. On the whole, the societal response to mental illness has in the main been extremely negative. The medical profession has been responsible for

numerous abuses of those entrusted to its care. A brief examination of the responses to mental illness on the part of the wider community suggests a similarly negative response. Mental illness is constructed in a particular way by the various discourses which impact on it, positioning those diagnosed with mental illness in a certain way. "The discursive practices which create the concept of madness mark it as fearful, as individual... as sickness; and they function as a form of social regulation" (Ussher, 1991, p. 11).

There seem to be two main discursive constructions of the person diagnosed with a mental illness, that of the insightful innocent and that of the uncontrollably violent 'maniac'. Support for the existence of the former category can be found in statements such as, "his mental disease brings him nearer to intuition and understanding" (Federn, cited in Feder, 1980, p. 98) and, "madness appears... as a level of psychic experience that produces an enlargement of perception and understanding" (Feder, 1980, p. 99). These ideas are found in literature. The Fool in Shakespeare's *King Lear* is a good example - someone not bound by society's rules and thus given space to express socially frowned-upon opinions. In this there is a sense of the 'innocent' who exists in a socially ordained space to give us insight into ourselves, but also as a symbol of pity. In this way, madness in an older sense (which Foucault, 1967, traces to the seventeenth and eighteenth centuries) represents not a confinement but a particular liberty - the liberty to speak one's mind without social constraint or sanction. Ussher describes this as "a vicarious enjoyment of those impulses to which we cannot allow free rein" (Ussher, 1991, p. 141). This idea has not left us, continuing to be found in popular fiction such as Kesey's *One Flew Over the Cuckoo's Nest* (Kesey, 1962). There is the suggestion that those who express themselves freely are 'mad.' It is ironic that such a view seems to abound when those with mental illnesses have experienced such a restriction on their liberty in the past. Thus, one idea of the person diagnosed with a mental illness is that he/she is an 'innocent',

particularly an insightful one.

The idea that the person diagnosed with a mental illness is particularly creative can be linked to this. This issue has been much debated (for discussions see Ludwig, 1995; Rothenberg, 1990), and there have been significant attempts to prove a greater level of creativity among those diagnosed with mental illness (*ibid.*). Some have even gone so far as to suggest that the idea of a link between madness and creativity has made 'madness' something to which certain artists aspire, in some way (Feder, 1980). The artist has a position as a social commentator or, at the very least, as someone who is meant to have some measure of insight into human nature. Thus there is a semantic link between the idea of the artist, or creative person as someone with insight into human nature and the idea of the insightful 'lunatic'. This idea has one particular manifestation as an interest in the art of those diagnosed with mental illness (See Gilman, 1995).

The other response on the part of society is to label the person diagnosed with a mental illness as violent. Arguably, it is this latter which has grown in importance in our culture. The fear involved in such a response makes it particularly important for the current discussion. All people in contact with Western society experience these stereotypes at some time, through ideas expressed in the language, i.e. in terms such as 'loony,' 'nutter,' and 'psycho,' or watching a film (e.g. *Silence of the Lambs*; *Psycho*), a television show, reading a book, etc. Newspaper headlines provide another example, with headlines such as "Deadly Crisis in Mental Hospitals - unstable patients released" (Viall & Johns, 2001) catching the attention and the imagination of the public in an evocative way, and possibly creating the impression that people diagnosed with mental illness are all psychopaths (see also Philo, et al., 1996). The fact that a person is more likely to be hospitalised after a publicised act of violence by a

person with a mental illness suggests one of the very real implications of these constructions (Brown and Rayne, 1989). It also suggests something of the subjective nature of diagnosis and treatment decisions. Psychiatrists are subject to the same pervasive influences as other members of society, and consequently experience the same fears. However, the peculiar power of the psychiatrist as someone who can remove the freedom of his neighbour almost at will (Haddox, 1986) makes this issue extremely problematic.

These images and ideas of the person diagnosed with a mental illness are in a sense brought together in the idea of the person with a mental illness, or the 'lunatic,' as an animal. Pinel described mental illness as a loss of reason, with 'Reason' being described as that faculty, "by which man is principally distinguished from the beasts" (Pinel, 1806, in Porter, 1991, p. 12). Consequently, it seems that to lose one's sanity is to lose one's status as a human being. the idea of the animal has connotations of both innocence and violence. Foucault identifies some traces of this animality hypothesis in Christian theology: "the scandal of madness showed men how close to animality their Fall could bring them; and at the same time how far divine mercy could extend when it consented to save man" (Foucault, 1967, p. 81). In the phrase, "the guilty innocence of the animal in man" (ibid., p. 82) there seems to be a link made between this image of the madman and the animal as a 'dumb animal' - the innocence and the violence in one. The language suggests that within every man (or to a lesser extent woman - as the one in a historical less powerful position) there lies the potential to be 'overwhelmed by his passions' i.e. to succumb to the animal nature within himself and turn into the savage, the madman. This powerful image persists in the writings of Freud, where the Id is posited as the repository of all our most basic urges, against which we are forced to constantly battle.

Some theorists have suggested that discourses around mental illness serve as a means of social control - "a label which acted to instill fear and functioned to control those outside the boundaries of insanity" (Ussher, 1991, p. 148). There is something about mental illness that has led to it being used as a catchall category for almost all forms of social deviance and 'social deviants' at some stage in history. Social deviants are people who either engage in socially unacceptable behaviours or who are cast as unacceptable to society itself. Homosexuals (Herman, 1995), women (see Ripa, 1990; Showalter, 1985; Ussher, 1991), blacks (Fernando, 1991) - all at some stage have sought to free themselves from being pathologised unjustly. This suggests the power involved in being able to define someone as mentally ill, because they are then subject to 'treatment', in the form of institutionalisation. The label 'mentally ill' or 'mad' has been used as a threat against minorities. For example if you are homosexual, you are 'sick' and 'mad'. Yet the fact that these other 'negative' labels have sought to distance themselves from mental illness suggests that in some way, mental illness has come to be the ultimate negative label, or identity. What seems to come through these ideas is the sense that what is at work is a process of creating an 'Other'. And that this 'Other' is seen as negative, undesirable and of less value or worth. This research will attempt to explore in what ways these ideas may have an impact on the experiences of people diagnosed with mental illness. And what, if any, influence this might have on how they interpret their rights.

In the context of disability, it has also been argued that social constructions have consequences for the way individuals see people with impairments and for the way people with impairments may see themselves. Watermeyer (2000) and Marks (1999) have made useful contributions to this area, by suggesting a link between social accounts of disability and understandings of the internal dynamics of such processes, building on psychoanalytic

theory (see also Finkelstein & French, 1993).

Shakespeare (1994) has called people with disability "dustbins for disavowal" (p. 283). The same could be said for the mentally ill. They represent a canvas on to which we can project our fears of losing our minds, our reason. Marks (1999) makes the point that people, "tend to treat madness as a state of irrationality suffered by certain people who have particular constitutions or who have had painful emotional experiences"(p. 141). This allows a space between 'them' and 'us', creating a buffer to allow 'us' to feel more comfortable. "'We are the freaks...not you. Not you!'" (Fiedler cited in Marks, 1999, p. 74). This quote seems to apply as much to the mentally ill as it does to Fiedler's circus freaks. Although we may all feel that at some time our grip on sanity may be loosened, those with mental illnesses seem to reassure us that we are not like them. "They (those diagnosed with mental illness) have an intrinsic fascination (for us) - possibly because they represent that part of ourselves which we most fear" (Ussher, 1991, p. 141).

Chapter 4

Theoretical Orientation III: The Intra-personal Dimension of Rights

This chapter explores the possible impact that social discrimination has on someone diagnosed with mental illness, and the implications that this has for their capacity to claim their rights. In this chapter, I also provide a summary of the central theoretical ideas informing the research question.

It is likely that the negative images that are evident throughout society impinge on the mentally ill person's sense of who they are, their self-identity. This could manifest, in the context of rights, as a reluctance to assert one's rights, because the individual does not feel 'entitled' in some way to make that claim. Arguing from a psychoanalytic perspective, Fanon (1967:1993) has discussed the effects of internalised oppression amongst black people. The consequences of such an internalisation are negative on the whole, as feelings of low self-worth bordering on self-loathing are likely to result. Support for this state of affairs in the experience of those diagnosed with a mental illness is found in the work of Wright, Gronfein and Owens (2000) who found evidence to support the claim that people diagnosed with mental illnesses exhibit low self-esteem.

People diagnosed with mental illnesses are subject to the same images of 'madness' and are part of the same social structure which constructs mental illness in a particular light. As such, they may carry the same kinds of phantasies regarding what it means to be 'mad'. It is possible that after the diagnosis, there follows a process of integrating this negative image (of someone with a mental illness) into the existing self-image. The implications for the practice of rights is that, as rights represent a claim to entitlement, there is a prerequisite that the

individual has a belief in her worthiness to receive such entitlement. Although it has already been suggested that this negative self-image may be a part of the mentally ill person's difficulty in asserting his/her rights, this body of theory suggests that the issue is complex, involving a reconciliation of pre-existing anxieties with one's sense of self.

It has been shown that being diagnosed with a mental illness has a negative effect on self-esteem, an effect which remains relatively stable over time, i.e. even after the diagnosis has been integrated (Wright, Gronfein and Owens, 2000). Some of the various strategies adopted to cope include, "keeping the information secret, educating people about the illness, or withdrawing from potentially stigmatizing (sic) social situations" (ibid. p 71). These strategies suggest that former inpatients share the generally negative view of mental illness which is pervasive in society, seeing it as something which should be hidden, which contributes to their isolation. Importantly, the integration of the identity of 'mental patient' into the self-identity seems to, "diminish feelings of mastery" (ibid. p 82). This might suggest that a person diagnosed with a mental illness will be unlikely to feel confident enough to assert their rights. A fuller understanding of this issue then needs to be developed. It is possible that some process of self-empowerment would be needed before rights will be claimed. The information outlined here suggests some of the ways in which the external, socially-pervasive negative images of mental illness might come to be internalised, and the negative consequences which this process has for the people concerned.

Internalised Oppression

The ideas on psychological or internalised oppression are found in the myriad social movements which exist to challenge the oppression of various groups within society. I have already elaborated on Foucault's idea of the Panopticon which has come to be internalised.

This provides each and every person with their own internalised 'police officer', and the sense that they are always under surveillance. "The psychologically oppressed become their own oppressors; they come to exercise harsh dominion over their own self-esteem" (Bartky, 1990, p 22). Bartky links the source of this oppression to the existence of stereotypes within society, and her emphasis is on the stereotyped societal images of women. According to her, these stereotypes are at odds with a sense of self, since stereotypes as a means of oppression must perforce be negative, and these negative images are difficult to reconcile with the individual's sense of who she actually is. The result is that a woman, "may find (herself) fragmented and the fragments at war with one another" (Bartky, 1990, p 25). In a similar way, the person with a mental illness may feel themselves split into the 'mentally ill/psychotic self' and the 'normal self'. Bartky suggests that, "(even) when economic and political obstacles on the path to autonomy are removed, a depreciated alter ego still blocks the way" (ibid. p. 24). The pervasiveness of these images creates a sense that this state of affairs is natural, and therefore no change is possible.

In Fanon's (1967: 1993) discussion of these issues in the context of racial oppression and colonialism, he suggests that these negative stereotypes are internalised and integrated into the sense of self. "Internalization (sic) refers to the process by which external, socio-historical reality is assimilated into 'internal and subjective reality'" (Bulhan, 1985, p. 196). Fanon (1967:1993) argues that, from an early age, children of all races are subjected to these images, which promote a distrust of the black person. For white people, this manifests as prejudice and aggression against black people. For the black person, the object of hate is her or himself. Again, the suggestion is that the negative reaction on the part of society to a negatively valued 'Other' is internalised by that 'Other'. It is possible that, in the context of mental illness, this negative internalised image is manifested as a sense of low self-worth.

This process is so effective and so difficult to reverse because it even involves the family. Fanon (1967:1993) traces the way that the language of the oppressor as well as the other cultural artefacts of the coloniser are revered within the home and children are encouraged to adopt them as their own. He makes reference to black schoolchildren in his homeland, a French colony at the time, referring to, "our ancestors, the Gauls" (p. 191). Plainly, at some point the black person will be forced to realise that it is they who have been portrayed as the savages that were conquered by these 'ancestors'. When these conquerors are viewed as representing good, the only position left open for black people is as the 'bad'. Coupled with prevailing social conditions, one witnesses, "the profound transformation of economic inferiority into subjective inferiority" (Bulhan, 1985, p. 196). It could be argued that not just economic but cultural inferiority, as constructed by the dominant group, contributes to the sense of 'subjective inferiority'.

Self-Perceptions of the Mentally Ill

In much the same way as Fanon (1967: 1993) describes the black person as, "a phobogenic object, a stimulus to anxiety" (p. 195), the same could be said of the person diagnosed with a mental illness. Such a person is subject to the stereotypes of 'the raving lunatic' and the psychopathic mass murder, which abound in popular culture. Once a diagnosis is made, the individual is faced with the task of integrating these images into her/his sense of self-identity, because these images, "work their way into one's mind and shape one's view of the world of the group to which one belongs" (Fanon, 1967:1993, p. 196). There is a trauma in being diagnosed with a mental illness, often coupled with the traumatic experience of having one's liberty removed and being institutionalised. The symptoms of the illness are often subjectively unpleasant as well, contributing to the trauma of the experience. These traumatic

experiences have then to be integrated into the experience of the person. It is important to realise that I am referring to a particular experience of mental illness, in a Western context. This experience is linked to the institution of psychiatry. It is also linked to the negative content of the stereotypes of mental illness which are pervasive in Western society. The individual has to make sense of the experience of 'having lost their mind'. They also have to integrate their sense of who they are, i.e. their personal identity, with the identity which has been created and which pertains to 'that type' of person; someone who is mentally ill, someone who is 'mad.'

The institutional experience adds another dimension to this. Here the person comes into contact with the practices of psychiatry, as well as an often frightening array of treatments, many of which are unpleasant to undergo. In the context of the institution, rejection of the identity is not an option. Goffman (1961) described the process of 'de-personalisation' at work in total institutions such as the psychiatric institution. In order to 'get better' the person has to accept the regimen of drugs and other treatments. But in accepting the medication, one is forced to accept the diagnosis, and along with it, the identity of being someone who has a mental illness. This process can be lengthy, involving a constant need to weigh up the risks of not taking medication, such as increasing the chance of a relapse, with the negative consequence of accepting one's position, i.e. the identity of someone who has a mental illness as well as the medication which goes with it. The medication in itself has both positive and negative aspects, since, while some medication may be successful in controlling symptoms, the correct medication may only be discovered through a process of trial and error and there are both physical and 'personality-related' side-effects (Edwards, 2000). Anecdotal evidence suggests that the medications influence the personality, which is one of the major reasons why people do not like taking them. It is suggested that each time medication is taken, it is

likely to reaffirm the identity as someone who is different, and the stereotypes associated with that identity are likely to become salient.

I have mentioned the diminished sense of mastery which may be linked to accepting the negative image of oneself as a mental patient (Wright, Gronfein and Owens, 2000). Other oppressed groups have adopted, as one strategy to counter-act this, trying to challenge this conceptualisation by identifying positive role models from their group. Thus, attempts are made to challenge the dominance of negative images within society. In the context of mental illness, this is more complex than for other marginalised groups, owing to the pervasiveness of the negative images and the fact that mental illness is so intimately linked to notions of self-identity.

In the context of rights, the individual as the rights-bearer is required to assert their rights against particular sources of oppression. This requires a certain degree of self-confidence, in all cases. In the context of mental illness, there is perhaps a greater need for self-belief. The fact that many mental illnesses are characterised by delusions and hallucinations on some level calls into question the claims made by someone with a mental illness. As mentioned, the power differential between doctor and patient contributes to this situation, assuming that rights are most salient in the context of medical practice. The weight of professional opinion, when stacked against an individual who at times may have experienced delusions, particularly of paranoia, or hallucinations, is likely to cause the individual a significant amount of self-doubt.

Self-Worth and Empowerment

If it is accepted that rights require a sense of self-worth as a precondition to the sense of

entitlement that rights operate to fulfil (Wellman, 1997), then it seems necessary to examine ways in which people might achieve this sense of self-worth. How does this empowerment take place, and how does it serve to improve people's chances of asserting their rights? The answer to the last question is fairly obvious. Once people have a sense of self-worth, they feel that they have the power to make demands. Rights are a demand-driven system of social justice - failure to demand or claim one's rights leads to those rights not being provided. But the way in which people become empowered is complex.

Empowerment suggests that people need to have a sense of who they are, i.e. a relatively stable and positive conception of who they are and what they need. In this regard, it seems that there may be obstacles for those diagnosed with a mental illness. They are subject to socially constructed negative stereotypes, which influence both their view of themselves and the way others view and respond to them (For a discussion, see Stein, 1997).

Central Theoretical Ideas Used in this Study

A review of the relevant literature suggests that the issues associated with claiming rights for those diagnosed with mental illness are complex. What does seem clear is that there are three main features of human rights which need to be considered when undertaking a study of the rights of those diagnosed with a mental illness.

1. The first is that rights are socially constructed. This suggests that issues around who has the power to make decisions about what constitutes rights may be relevant. It also suggests that rights are subject to debate and development over time. Furthermore, as socially constructed, different aspects of rights may be emphasised by different groups.

2. Secondly, rights function as both legal and social entities. The implication of this is that the way the legal system has dealt with mental illness is relevant, but that the social dimensions of mental illness are also relevant. As a study within the domain of psychology, it is this latter issue which will form the major focus of this thesis. In particular, since rights can be socially enforced, questions arise around how society responds to those with mental illness and what implications this may have for the assertion of rights on the part of those diagnosed with mental illness.
3. And finally, rights are essentially claims that *individuals* have to make. As such, issues around the identity of those diagnosed with a mental illness will need to be examined, particularly focussing on the idea that a sense of entitlement may be necessary to claiming one's rights.

Chapter 5

Method

The aim of this study was to explore how people with a mental illness understood their own rights in society, as well as the opportunities and challenges they perceived in actualising these. In order to access their understanding effectively, I ran a series of workshops for two groups of people diagnosed with mental illness. These workshops were designed to elicit the participants' views about their rights as well as involve them in an educational process in relation to their own rights, in line with the action research orientation that informs this study. The research method focussed on the experience of people diagnosed with mental illness, with the aim of shedding light on some of the ways that an understanding of rights comes to be shaped by their experiences. It also attempted to shed light on the process of marginalisation experienced by people diagnosed with a mental illness.

The questions that framed my approach to the research were as follows:

1. How did the participants understand their own identity as a person diagnosed with a mental illness?
2. What value did they ascribe to rights?
3. How did they describe their rights and envisage them working in their everyday lives?
4. What opportunities or difficulties did they experience in attempting to actualise their rights?

The analytic background for these questions was provided by the literature reviewed in the previous sections. Through the analysis, I hoped to explore the ways in which the participants in this study might be influenced by the legal framework within which their rights are

constructed, the social context in which they are operationalised, as well as the issues associated with their own psychological experience of being able to claim these rights as their own.

The Research Paradigm

Guba and Lincoln (1994) suggest that, “questions of method are secondary to questions of paradigm” (p. 105). One’s paradigm is, “the basic belief system or worldview that guides the investigator, not only in choice of method but in ontologically and epistemologically fundamental ways” (ibid.). Thus defined, one’s paradigm necessarily precedes any debate about method. How one views the nature of knowledge and its origins (epistemology), as well as how one views reality (ontology) define how a researcher approaches any research project, including what research projects are chosen and how the research is framed and conducted. It is for this reason that it is necessary to locate myself within a research framework

The positivist approach to research holds that a researcher should remain anonymous and separated from her or his research, in the interests of objectivity. Fine (1994) draws attention to the ways that the creation of this ‘hidden observer’ gives the researcher what might be described as ‘godlike’ power, as a faceless manipulator of variables. This power differential would be particularly problematic in the context of working with a group who are already marginalised within society. It would also be untenable within an action research framework. Research is not independent, since it is rooted in a particular social context. Furthermore, a researcher cannot be totally independent, since he/she is always influenced by the contextual factors of his/her own biography that they bring to the research process. Such a biography includes details of demographic characteristics as well as personal experiences that may have

a bearing on the research. I will deal with the specifics of my own biography when engaging more fully with reflexive issues which emerged during the course of this research.

In terms of a theoretical tradition of paradigm within which to locate this research, I would argue that my own orientation, which shapes the orientation of this research, falls somewhere within the Constructionist/Interpretivist paradigm, as defined by Guba and Lincoln (1994). A constructivist ontology assumes a variety of realities which can be described as, “mental constructions, socially and experientially based” (ibid. p. 110). These realities are negotiated through a process of interaction. In terms of this research, the focus group method would seem particularly suited for obtaining an understanding of the negotiation between various positions. The procedure of the research was also geared towards fostering an emerging understanding of the relationship between rights and everyday social interactions. The ontological standpoint has implications for the constructivist understanding of epistemology. There is the assumption that, “findings are literally created as the investigation proceeds” (ibid.). This resonates again with the idea of emerging understandings which the focus group method facilitates.

The methodology which is thought to follow from these epistemological/ontological understandings is one which aims for, “a consensus construction that is more informed ...than any of the predecessor constructions” (Guba and Lincoln, 1994, p. 111). The methods adopted are assumed to be largely “hermeneutical” and “dialectical”(ibid.), drawing attention to the circular nature of research, and its interactional elements. This is, however, only one of several variations on the idea of constructivism/ constructionism (see Schwandt, 1994 for a discussion of some examples).

One problem that flows from an acceptance of constructivism is that it opens the door to an acceptance of relativism. While it is difficult to refute these claims ontologically, it is necessary to reject them for pragmatic reasons. In particular, an acceptance of relativism implies that all versions of reality, i.e. all constructions, are of equal value. This provides a space for the acceptance of situations in which the status quo is maintained, to the detriment of vulnerable groups. As such, in research such as this, it is not acceptable. A research orientation which removes the impetus for social change is untenable in the light of the aims of this research, one of which is to empower the research participants, through developing a greater understanding of the meaning rights have for them, and trying to challenge the marginalisation of people diagnosed with mental illnesses within society. Many researchers have begun to suggest that the social contribution of research is one of the few criteria by which we can judge its value (see Kincheloe & McLaren, 1994).

Another important dimension in the research process is the issue of the view of the researcher which is adopted. The positivist and post-positivist position is that a researcher should be a “disinterested” observer (Guba and Lincoln, 1994). This is problematic owing to the embeddedness of the researcher in the process of knowledge creation. Guba and Lincoln (1994) suggest that critical theorists view the researcher as someone with an, “expanded consciousness” (p. 115). The researcher is thought to act as an “advocate and activist” (ibid. p. 112). This view, and Kincheloe and McLaren’s (1994) description of critical theory, emphasise the power of the researcher in the research process in a way which I feel is somewhat closer to the realities of the research process. Constructivist researchers, as identified by Guba and Lincoln, are thought of as facilitators of “a ‘multivoice’ reconstruction” (1994, p. 115). However, in the research process, the researcher ultimately makes choices with regard to what to include, how the voices are included, i.e. represented,

and with what intention. At the same time, research writing is constrained by stylistic and language issues. Research is always written with an intention in mind, which is the creation of an argument for or against a certain construction. The method of arriving at and justifying one's constructions varies, and may even be misunderstood by the researcher. But research is a dialectical and dialogical process, and as such involves an argument or negotiation for a certain position. I would not argue against striving for a "multi-voice" construction, but would caution against viewing any research as truly 'multi-voice', given that, in instances of debate during the course of the research process, it is likely to be the researcher's voice which dominates.

To bring together the key features of the particular approach adopted in this research, I feel that what can be known, at best, are consensual constructions of 'reality'. Yet, as consensual or inter-subjective, these constructions take on a large degree of significance, being treated 'as if' they were real. This opens up a praxis for transformation (which I, in common with critical theorists such as Kincheloe and McLaren, 1994, regard as one of the most fundamental criteria for judging the value of research). The questions raised by this research were informed by my particular paradigm. The way the questions have been framed influence my choice of method as well. "What meaning does the idea of human rights have for those diagnosed with a mental illness" as a research question serves to direct attention to methods concerned with understanding the process of meaning-making. This suggested that I examine a range of qualitative methods, particularly those in line with the hermeneutic approach.

There were other considerations when deciding on an appropriate method, which were inherent in the aims of the research, and my understanding of the field. People with mental illnesses are perhaps one of the least powerful groups in society. The majority of research

involving the mentally ill deals with ways of improving their treatment, diagnosis, etc. This has the effect of creating an historic focus on their illness rather than on their lives. The value of adopting a qualitative research approach is that it gives a clearer picture of what is happening at the micro-level, where power relations are played out in everyday life. This research sought in some measure to address the absence of the experience of the mentally ill from research.

As mentioned initially, the method adopted involved the use of focus groups, informed by some of the principles of action research. This reflected a concern for the issue of power. Punch (1998) identifies the feminist influence on qualitative research as primarily responsible for the fore-grounding of issues of power in research. The feminist critique, “argues that knowledge should be used for emancipatory purposes” (Denzin, 1989, p. 27). Of central importance to the current study was the fact that the researcher has power over the participants, in the sense that the researcher has the power to make decisions about the research method. The researcher also ultimately bears responsibility for interpreting the data. By viewing the participants as collaborators in the production of knowledge to an extent, I have tried to diminish the power difference between the research participants and myself. However, I realise that I ultimately make decisions regarding the interpretation of data which may not necessarily reflect the views of the participants. To offset this inevitable aspect of research, I have attempted to give something back to the participants, in the form of information concerning their rights. This research will also be given to the Cape Consumer Advocacy Body (CCAB), a group of mental health service users who focus on promoting awareness of mental illness and the issues faced by people diagnosed with mental illness. I feel these steps reflect an acknowledgement of the power differentials in the research process. The other way in which an attempt has been made to disrupt the power differential involved

in research is through the use of feedback in the sessions and to CCAB as a whole. As Mergendoller (1989) suggests, “the veracity of interpretive research emanates from debate and consensual agreement” (p. 127). Research is a circular process, and viewing participants as co-creators of knowledge makes the use of feedback a necessary dimension of the research process.

Action Research

Within these broader considerations of the research process, the approach which was adopted in this study could be characterised as having an action research orientation. Such an orientation was appropriate, since it “highlights the political and politicizing (sic) nature of the research process.” (Punch, 1998, p. 143). The literature outlined above seems to suggest something of the way those diagnosed with a mental illness are marginalised within society. Consequently, there was a need to empower the research participants, both by providing them with information that they might use and by allowing them some measure of control over the research process. Action research offered an opportunity to achieve these aims (Hart & Bond, 1997). It must be pointed out that these are two separate aims. The first is what might more correctly be termed action research, since it seeks to make changes to people’s behaviour i.e. to challenge power relations in the social world directly. The other aim relates more specifically to the issue of power in the research process, since it is concerned with challenging the existing power differentials between researcher and participant (Punch, 1998).

Action research proceeds from the assumption that research, “processes should be applied in ways that benefit all participants directly” (Stringer, 1999, p. 7). This suggests a concern for the issue of power in research. In the context of this research, it is particularly appealing,

since those with mental illnesses are a relatively powerless group in society. The aim of an empowerment orientation is to “(enhance) user-control and (shift the) balance of power” (Hart & Bond, 1997, p. 40). The focus on the meaning that certain ideas have for the participants may also serve to illustrate the link between their experiences, and the meaning they attribute to certain concepts. In this way, relevant experiences can be discussed, and situations in which rights were felt to have been violated are likely to be identified. People in such situations may benefit from fostering a greater awareness of human rights.

The Use of Focus Groups

The action research orientation does not automatically lead to a particular method, as a variety of methods can be used in action research (Denzin, 1989). However, Wilkinson (1999) suggests that focus groups are particularly suited to research, “with underrepresented social groups” (p. 233) as well as “action research” and “consciousness raising” (Wilkinson, 1999, p. 234).

Focus groups were felt to be the most appropriate method for this research. My interest was in the meanings of human rights for the participants, and as such I was interested in how these meanings emerged, were negotiated and agreed on. “(The) social context of the focus group offers the opportunity to observe the coconstruction (sic) of meaning and the elaboration of identities through interaction” (Wilkinson, 1999, p. 229). The group dynamics at work and the debate and negotiation which focus groups encourage seemed to represent the best opportunity to gain an insight into this process. Focus groups also offered the advantage that a range of opinions and viewpoints would be presented together, and in this way could be compared and contrasted, both during the group discussions and in the analysis.

The one-on-one interview was another possible method which might have been adopted for this research. However, for the purpose of the current research, focus groups have several advantages. They are particularly useful for exploratory research (Vaughn, Schumm and Singabub, 1996). The information generated in groups has specific advantages over that generated in one-on-one interviews. The “loosening effect” (Vaughn, Schumm and Singabub, 1996, p. 19) is one advantage, reducing the pressure on each individual to provide detailed information, which diminishes the similarity between our interaction and the one-on-one interaction between mental health practitioner and patient. The anonymity provided by the group allows each participant to “disclose more freely” (ibid.), particularly relevant in this instance where participants might have been wary of possible repercussions of disclosure. The group allows participants to form opinions - “the open exchange of different perceptions may spark new opinions or strengthen present convictions” (Vaughn, Schumm and Singabub, 1996, p. 20). Furthermore, as Morgan (1997) observes, the group interaction allows a direct comparison of participants’ attitudes and perceptions. This was particularly useful in the current research, since it gave insight into the way an understanding of rights develops through people’s interactions. The meetings were often characterised by debate and negotiation, suggesting something of this process.

Another significant advantage which focus groups have for the current research is that, in the group, the power of the researcher is diminished. Authors who provide guidelines on how to conduct focus groups may view this as a problem, emphasising the need for the moderator to remain in control (See for example Morgan, 1997 and Greenbaum, 1998). However, other researchers, particularly those having a feminist (e.g. Wilkinson, 1999) or disability (e.g. Barlow & Harrison, 1996) orientation suggest that this is an advantage of the method, since it empowers the participants. This is in line with one of the ideals of action research (Hart &

Bond, 1997). As Wilkinson (1999) notes, “focus groups shift the balance of power and control towards the research participants” (p. 230).

Participants have the feeling of being involved in the research and in shaping and constructing meanings together (Wilkinson, 1999) which in itself is often empowering. I tried to give participants some say over what was discussed at times and over some of the logistical details of the workshops. Morgan (1997), in discussing his research with survivors of heart attacks, shows how the group context can provide an opportunity for support, which benefits the participants, and aids the discussion of sensitive topics. Support and the experience of being listened to could also be seen as empowering, and this was a feature of the group discussions. The potential for empowerment which focus groups offer is thus conducive to the action research orientation of the research.

There are however, several disadvantages to focus groups. From a practical point of view, there is difficulty in organising the logistics of gathering a group of people in one place (Morgan, 1997). Decisions with regard to the site for the focus groups can affect the quality of the data and in this case might have been compounded by difficulties with regard to access to transport. Perhaps the major drawback of the focus group as a research method is that it requires some degree of skill on the part of the moderator in order to facilitate the discussion, while guiding it in directions useful to the research. Greenbaum (1998) pays particular attention to this issue, giving specific guidelines to would-be moderators. While this does seem a problem, Wilkinson (1999) suggests that it may be an advantage, questioning the desirability of the researcher having too much control. For this research, the emphasis on a quite unstructured approach initially circumvented this. Pointing out the emphasis of each session and making it clear that subsequent groups would be more structured also helped to

minimise the problem. But ultimately, with sufficient preparation (and guidance from the supervisor), the negative effects of my inexperience as a moderator were minimised, and it was felt that the advantages outweighed the disadvantages.

Participants

Accessing participants

The participants were accessed through the Cape Consumer Advocacy Body (CCAB). This method of accessing participants was decided on due to the ethical difficulties that accessing participants through case records and other methods involving the mental health system would have presented. This method was also convenient, since CCAB meets once a month. The participants volunteered to participate in the workshops. While this method may have resulted in groups with more interest and knowledge about rights than ordinarily found, it also had the advantage of increasing the likelihood that the people involved would be open and talkative. They would also be likely to have an interest in the subject matter, which would make engagement on the issues easier.

There were two groups of participants. The first group consisted of five participants, two of whom were female and three were male. They are all Coloured, four from poorer areas in Cape Town's Southern Suburbs and one from the relatively more affluent Northern suburb of Belhar. The women had both been diagnosed with bipolar mood disorder and the men were all diagnosed with schizophrenia. The second group were all female, two were black, Xhosa-speaking women and four were Coloured, speaking English and Afrikaans at home. All lived in the Southern Suburbs area. However, one of the participants took part in both groups, because she volunteered to accompany a participant in the second group who was reluctant to travel on her own. It was decided that her inclusion in the second group was an acceptable

compromise (The reasons for this are explained further in the section dealing with the group process). Two of the participants in the second group had been diagnosed with bipolar mood disorder, as well as Jean, the woman who participated in both groups. Two of the participants in group 2 had been diagnosed with schizophrenia and another with major depressive disorder. All participants had spent varying lengths of time in institutions and the length of time that they had spent living with the diagnosis varied from over twenty years to two years. They are all currently receiving treatment, whilst living in the community. All participants were on Disability Grants, although some indicated the intention to work, and some claimed to do odd jobs for extra money. One participant was physically disabled, requiring a cane to walk and having difficulty climbing steps. The ages of the participants ranged from twenty-one to fifty-six years old.

Further Information on Participants

I have decided to make use of pseudonyms for my participants, rather than to describe them as participants 1 - 10. The reason for this is that I felt that it tied in with one of my aims in this research, which was to give 'voice' to the experiences of those diagnosed with a mental illness. I have also included some biographical information on the participants. The objective is to give the reader a sense of exactly who the participants were, and in this way introduce the reality of their situations. As action research involves working together to create knowledge, it would seem dishonest not to give the reader some sense of who the co-creators of this research were.

Group 1

Ebrahim is a fifty-six year old Coloured man, from Bridgetown in the Cape Southern Suburbs. He lives at home with his mother. He was diagnosed with toxic psychosis in the late

Seventies, the result of alcohol and marijuana abuse. The diagnosis was later changed to schizophrenia. He has had several admissions at Valkenberg, although he was unsure of exactly how many. He is currently unemployed although during the course of the research managed to secure himself a part-time job. He receives a Disability Grant.

Robert is twenty-seven, and also lives in Bridgetown. He lives in a shanty in the yard of his mother and step-father's house. He is Coloured, has been diagnosed with schizophrenia and has had several admissions at both Lenteguur and Valkenberg. He felt that mental illness was the result of the abuse of drugs such as marijuana. He also indicated that he was unemployed, and lived on a Disability Grant administered by his family.

Ben is twenty-five, and from the same suburb in Cape Town as both the previous participants. He is Coloured and lives at home with his parents. He has been diagnosed with schizophrenia and admitted to Valkenberg on about five occasions. He has at times participated in the work program at Fountain House, a not-for-profit rehabilitation program for people diagnosed with mental illness, in Observatory in Cape Town. He has also been employed at various times for short periods. However, at the time of the research being conducted, he was unemployed.

Jean is thirty-one, Coloured and lives in Lavender Hill, in the Southern Suburbs. She lives in a "Wendy-house" on the property of another older woman. A former employer bought the house for her. Jean had been a pre-school teacher for several years both before and after her first admission. However, after an incident in which she attacked a child, she was forced to give up teaching. She had also worked as a care-giver in a retirement home. She said that her family wanted little to do with her now, and she supported herself with her Disability Grant.

She had been diagnosed with bipolar mood disorder and admitted on several occasions, to Lenteguur, Valkenberg and Elizabeth Donkin hospital in the Eastern Cape.

Leanne is a twenty-one year old Coloured woman who lives with her family in Belhar, in the Northern suburbs of Cape Town. She was diagnosed with bipolar mood disorder while still at school and had been admitted to both private and later, State institutions. She receives a Disability Grant, and has never been employed. She would like to study further, but is nervous about her ability to study, and more particularly her ability to handle the pressures of studying which may increase her chances of a relapse.

Group 2

Florence is a forty-seven year old Xhosa woman from the Eastern Cape, who now lives in Observatory. She was diagnosed with a Major Depressive Disorder after the death of her mother several years ago. She lives in a house with other people who have been treated at Valkenberg. Her three teenage sons cannot stay with her at this house, and she wants to move, but her options are limited by the fact that she is on a Disability Grant, which does not pay enough for her to find accommodation elsewhere. She does volunteer work with street people, running a soup kitchen in Observatory for them.

Maria runs the soup kitchen with Florence. She is a Xhosa woman, and was diagnosed with bipolar mood disorder while still in the Eastern Cape, but now stays in a house in Observatory run by a foundation which assists people diagnosed with mental illnesses. She also lives with former patients and is supported by a Disability Grant.

Daphne is a Coloured woman who lives in Mitchell's Plain, near her son and his wife. She

rents a room from a retired woman. She was diagnosed with schizophrenia shortly after the death of her mother, but has not had a relapse in several years. During the course of the workshops, she decided that she would ask her doctor if she could gradually begin to reduce the dosage of her medication and also start working again, for the first time since she suffered an initial relapse. She was still receiving a Disability Grant at the time of the study although she said that she no longer wanted to depend on the State.

Sophia is a friend of Jean's, and I contacted her through Jean. She had been diagnosed with bipolar mood disorder several years ago, and had suffered a number of relapses. She was very nervous about participating in the research as it meant that she would have to travel. For this reason, Jean agreed to travel with her and sit in on the sessions. This illustrates some of the difficulties of living with a mental illness. Sophia had been very isolated before Jean's intervention, not being able to travel on her own for some time. In a resource-poor country such as ours, this is a particular problem. She was extremely reluctant to make use of public transport, but this was the only form of transport available to her. However, during the course of the study, Sophia felt confident enough to travel on her own on one occasion, when Jean was unavailable. Sophia is a Coloured woman who lives at home with her parents in the Southern Suburbs.

Diane is Jean's next-door-neighbour. She is Coloured, and volunteered to take part in the workshops ostensibly because she was house-bound, and did not have the opportunity to meet very many people. She was very shy during the course of the meetings, but in informal discussions after the final workshop, she said that she had enjoyed taking part. She had been diagnosed with schizophrenia after the birth of her only child, and she was not given custody of the child as a result.

Procedure

Once participants were contacted, six out of the eleven were interviewed briefly at Cape Mental Health Society and the rest were interviewed over the telephone. My first objective was to allow participants to raise questions with me and reassure them about the research, as well as to get an understanding of who they were and what interest they had in this research. The second objective was to obtain the background information outlined above, and to ensure that they would be suitable for the research. My concern was to screen out people who were too ill to participate in the discussions. The use of interviews also were part of the action research orientation of this study, since it gave participants an opportunity to voice their opinions on what they would like to discuss in the focus groups. All participants were subsequently asked to give their consent, after having been informed of the purpose of the research. It was also made clear to the participants that what was discussed in the workshops was to remain confidential.

The interviews highlighted the fact that there was a desire for more information on rights relating to the care of those diagnosed with mental illness. We also discussed rights in relation to the work environment, which came across as one of the key interests of some participants in the interviews. It became critically clear that rights were not an issue which seemed well understood. Participants looked to me to teach them about their rights. Furthermore, what was understood about rights was limited to a number of settings, particularly in relation to the institution and employment.

The ten participants were divided into two groups. The purpose of this was to allow a comparison between the groups, to improve the validity of the research, since if similar findings were felt to emerge from both groups then there would be greater validity. Two

groups had the added advantage that, if one group failed to produce sufficient data, it would hopefully be possible to supplement this with information from the other group. An unintended benefit for me personally was that the two groups afforded me an opportunity to see first-hand how different group dynamics can affect the outcome of a research process.

The second group consisted solely of women, and for this reason had a different character to the first group. These differences notwithstanding, the experiences of the participants in relation to their rights were quite similar, and for this reason, in my discussion, I have not differentiated between the experiences of the groups, although the experience of traditional methods of dealing with mental illness are limited to certain participants.

Six focus groups were conducted with each group of participants. These were held twice weekly at the Cape Mental Health Society buildings in Observatory. This venue was chosen because CCAB is run under the auspices of the Cape Mental Health Society and it was an accessible venue due to its location in the Southern suburbs, near a railway station. It was also a venue that I felt the participants would be comfortable with, as most of them had been there and knew some of the staff.

The meetings were styled as workshops, to reinforce the sense that they were working groups, in which participants and I had the shared aim of engaging with the subject of rights and some of the realities the participants faced, and to act as co-creators of knowledge and understanding. What seems apparent from the literature, and which flows from my own interest in this ostensibly legalistic subject from a psychological perspective, is that rights cannot be separated from issues of identity and the social context in which they are debated and claimed. Consequently, I encouraged participants to talk about their experiences of living

with mental illness in order to get some idea of how rights relate to this context.

The first three meetings were taken up with discussions of the three different scenarios I devised, relating various incidents which I had an indication would resonate with incidents in their lives. These were informed by my previous work in this area as well as the interviews I conducted with participants prior to the focus groups. The scenarios are contained in the appendix. Briefly, they deal with a job interview situation, a social interaction in a clinic and a relationship between a man and a woman. Consequently, they each allowed a discussion of certain issues, related to stigma, rights and living with a mental illness. This was useful as an introduction to the topic, since it afforded participants the opportunity to discuss aspects of their lives. This sharing also served as a way of 'breaking the ice' within each group. It provided a context within which it became possible to locate certain issues pertaining to rights. From here, it was possible to develop an understanding of what rights were, and for the purposes of this research, what aspects of human rights participants drew on in order to make sense of the experiences in their own lives.

The fourth session focussed on rounding-off the work begun in the previous sessions by summarising what had been said. The purpose of this was, in line with some of the ideas underpinning action research, to determine if the conclusions I drew had a meaning for the participants. This session also raised the issue of rights in particular, asking general questions along the lines of what rights are and how the participants experience them.

The fifth session introduced the draft Mental Health Care Bill, which has been described as a more "rights-based" approach to mental healthcare (Freeman, 2001). In particular, Chapter Three (Rights and Duties relating to Mental Health Care Users), was discussed. This was

partly something which I felt needed inclusion as part of the action research orientation, as I felt it was my obligation to the participants to include this, to educate them about forthcoming legislation, which they had difficulty accessing. It thus resonated with the empowerment orientation of the current research. It also allowed an insight into the participants' views on the document, and the rights that were being promulgated, ostensibly on their behalf, at the time.

The final session was for the purpose of wrapping up outstanding issues, revisiting some of the discussions and conclusions and re-framing some of the negative incidents in a way that would allow participants to think about the possibilities for change. This was an orientation of the workshop process as a whole. I tried to ensure that the issues were addressed in a way that allowed participants to identify where their strengths lay. I also encouraged the already strong levels of support which participants formed with one another over the course of the meetings.

Analysis

The focus of the analysis was on the ways in which people diagnosed as having a mental illness construct an understanding of their rights. Particular attention was given to the question of ways in which their status as 'mentally ill' and the experiences that this has entailed affect these constructions. The data were also examined for evidence in support of the theoretical orientations outlined above. Perhaps the most critical question informing the analysis is "what meaning does the idea of human rights have for those diagnosed with a mental illness?" The questions outlined above follow from this, since the way these understandings are constructed and used reflects as well as has implications for the use to which the idea of 'rights' is put.

It is difficult to separate the analysis from the procedure itself, since my analysis took the form of an emerging understanding, which developed through the process of attending the workshops and discussing the issues first with one group and then with another. Hence, my role was far from neutral, as I found myself asking questions of the second group to clarify issues which had been raised in my mind by the first group. Thus, data collection and data analysis are in a sense intimately bound together, and separating them out seems somewhat artificial. My aim in the analysis was to develop an understanding, both of the context within which the participants find themselves as people living with a diagnosis of mental illness, and the meaning that this has for them. From this, my interest was on establishing links between their experiences and the meanings that they attribute to human rights - how do the participants make sense of their position and integrate their understandings and experiences into a framework, through which their rights are interpreted and made sense of.

I started by transcribing the focus group sessions. This in itself involves an interpretive stage, since decisions are made about how to represent sounds, pauses, etc. Langford (1994) suggests that transcription can never capture the conversation exactly, since it is impossible to convey tone, and non-verbal cues which are present on the taped recording. From here, I went through the transcripts reading for key phrases, and elements of the discussion which resonated with my sense of the meaning which participants and myself had sought to give to their experience of being diagnosed with mental illness and to human rights. Again, it is important to recognise that the analysis of the transcripts takes place after the initial analysis has been done, during the course of the data gathering process. I made notes after each focus group session, and thought about what had been discussed. I also sought to summarise what had been discussed in the groups at various stages in the workshops, to validate my

interpretations, and to remind participants of what we had covered. These steps can all be seen as stages in analysis, although perhaps not part of the formal 'analysis' stage of research. It is necessary to divide research into these phases, for the sake of a methodical, stage-by-stage approach. Yet, it is not so clear-cut, reflecting the circular nature of much social research (Mergendoller, 1989; Packer, 1989). This initial analysis allowed me the opportunity to clarify issues, leading to richer data.

After picking out key phrases, I sought to organise them into themes, under various headings. This process was a relatively laborious one, since the themes were not always clear. I also found that the themes in many ways reflected the approach of using scenarios depicting certain fictional events, because they were grouped around, for example work, family and the mental health system. This again challenges the idea of analysis and other phases of research as being completely distinct.

After this, I attempted a draft interpretation, in which I sought to interpret the themes and ideas in light of the theoretical framework that I had outlined initially. From here, a circular process of interpretation and re-examination of the data started, which was informed by an understanding of data analysis as a hermeneutic process (see for example Packer, 1989). I found it necessary to return to the data at several stages, each new reading adding some new nuance to what I had found and thought I understood. At one stage, I did a somewhat cursory content analysis, searching for words such as human rights etc. This more quantitative approach yielded insight as well, reinforcing the necessity to not be overly dogmatic in approaching analysis. My analysis was also informed in some measure by my interest in discourse and language. But in general, it would best be described as reading for meaning, rather than for particular aspects of language or style.

The practice of repeated readings also leaves the “lingering anxiety (that) the final model may not provide the best fit to the phenomena under study” (Mergendoller, 1989, p. 128). I share Mergendoller’s anxiety: “Did I quit too soon?” (ibid.). I also recognise that the ideas that came through in the analysis reflect ideas that seemed to be running through the theoretical ideas I had identified at earlier stages. This is a feature which reinforces the idea that “the researcher begins with preunderstandings that affect how he or she perceives the world and selects ‘data’” (Addison, 1989, p. 41). These are issues which speak to the validity of the research.

Validity

The validity of this research is dependent on two sources. The first of these addresses the questions, ‘Is my interpretation valid’ and, ‘Have I captured the experience of the participants adequately’. This flows directly from the understanding of this research as an attempt to understand the meaning certain concepts, such as human rights, have for the participants. To assess whether I have captured this, I strove to make feedback a part of the research process. At the conclusion of each session, the key features of the discussion were summed up. This allowed an opportunity for feedback on what had been achieved. The group context also allowed issues to be negotiated and consensus was reached on many of the issues. This process allowed me to reflect my understanding of what the participants were saying, and in this way ensure that my understandings were valid. The feedback process was continued through a session devoted to summing up what had been discussed. The research has also been presented to CCAB, with some of the participants present. This allowed feedback at a later stage of the process, giving participants a chance to reflect on some of the conclusions that had been reached. On completion, a copy is to be provided for CCAB to continue the

process of validation through feedback, and to contribute to the usefulness of the research for participants, in line with the action research orientation of this study. This in itself falls within the scope of action research, serving as it does to highlight the 'blurring' of the distinction between the researcher and the participants and stressing the idea that in the research process, knowledge is jointly created (Stringer, 1996).

The second form of validity is more particularly related to the research process, dealing with issues such as whether the research method was a valid one' and whether the process was acceptable. Here the judgement will rest on how members of the research community view the method. Altheide and Johnson refer to this as "validity-as-reflexive-accounting" (Altheide and Johnson, 1994, p. 489). This suggests the need for a clear, reflexive account of the process of the research. It is this understanding which informed the discussion of my position in relation to larger paradigms of research. It also necessitates a reflexive account of some of my experiences and emotional reactions during the course of the research. This is particularly necessary if it is accepted that emotion "is present in the observations that are gathered" (Denzin, 1989, p. 29). This also flows in part from my understanding that a researcher should be willing to air her or his "dirty linen" (Lincoln, cited by Fine, 1994, p. 75) in the same way that the participants were willing to air theirs by being honest and open during the course of this research.

Reflexive Account

As an initial step towards locating myself, I will first deal with the demographic details. I am a 23-year old, English-speaking, white male, from a middle class background. This thesis forms part of my MA in Psychological Research. As such, I differ from the participants in several ways. I am younger than all except one of them, from a different social class, and

better educated. I also speak a somewhat different dialect of English, given that the participants who said that they were English-speaking often made use of Afrikaans words. I am also from a different racial background, which shapes and underlies a significant degree of interactions. I also have never been diagnosed with a mental illness. I did not grow up in the Cape, and having lived here for only a year at the start of the research, I was also not altogether familiar with the organisation of the mental health services in the province.

My interest in the field of study was linked to my decision to study psychology. I was always more interested in the more serious clinical aspects of psychological and mental dysfunction. There can be little doubt that I approached this research with some of the same ideas about mental illness that exist in popular culture. Yet I have worked with people diagnosed with mental illness in the past. I completed my BA (Honours) research project on a similar topic. I also did volunteer work in a psychiatric hospital outside Pietermaritzburg, which dealt exclusively with State patients. Here, some of my fears and anxieties around mental illness, particularly the violent aspects of mental illness, were first acknowledged.

Another reason for my interest in this subject was the idea that mental illness is a spectrum, an idea I first came across in the work of Carl Jung (see Jacobi, 1942: 1968). This suggested that there might be aspects of mental illness in everyone. Perhaps, in some way, I wanted to try and confront my own 'madness'. I also in a sense 'fell into' this research, by accident. I approached a supervisor in my Honours year about the possibility of doing work with someone who had just been released from a psychiatric hospital after twenty years. From here, I moved into an examination of the mental health system, and those diagnosed with mental illness. This work is a continuation of that. My interest in human rights stemmed largely from my interest in how larger issues and concerns come to have an effect or have

meaning for the lives of 'ordinary' people. Human rights is in some sense one of the defining ideas or motions in recent history. I was interested in what this meant for someone who was not a human rights activist in the usual sense, or a politician. I was also intrigued by Foucault's idea that "nothing is ...fundamentally liberating". This seemed to me to suggest that how an idea is actualised and how people respond to it is the measure of its value.

When I began the data gathering, I was nervous about my ability to handle a group discussion. I was not overly anxious about working with people that might be described as 'mad', since I had worked with former psychiatric patients as well as in-patients before. I was also in a venue where there were better-qualified people available, should an emergency arise. One issue I did feel the need to address, for myself, was the issue of trust. Dworkin (1992) suggests that a researcher should be cautious about believing what someone diagnosed with a mental illness tells them. This was somewhat unnerving, given that I was about to base my research on what such people were to tell me. But I found that it was not an issue as the research progressed. This in itself has some bearing on the research questions, since it seems to reflect the belief that people diagnosed with mental illness cannot be trusted in terms of their accounts of events. This ties in with the possibility that people diagnosed with mental illness have the experience of having their viewpoints discounted, a situation likely to foster self-doubt.

As the research went on, it was impossible to remain unmoved by the stories which unfolded. The groups provided a context within which participants shared many traumatic moments. I was concerned about my ability to contain such moments, and at one time I feel that I failed to do so adequately, as one participant left feeling quite upset. But we discussed this in the next session, where she voiced her concerns, and we adapted the groups to try and allow time

to 'come down' after each session. We also made a point of having coffee together at the end of the session, to chat and relax. There was a sense that the experience of mental illness is a very sad one, and this evoked strong feelings of empathy on my part. This became clear in my analysis, where I found myself struggling to portray participants in a positive light at times. I recognised that I may have had the tendency to portray the participants as 'all-good.' The other issue which emerged in this regard was a strong desire to help, which extended beyond the research setting.

It must also be acknowledged that I benefited from the workshop process, having learnt from my participants, and been forced at times to re-evaluate pre-conceived ideas. At another level, I must point out that there is some feeling of guilt on my part, since in a sense I am using what was shared for my benefit, to earn my degree. Yet, this is part of the research process, in which the participants and myself made an agreement before we began, which acknowledged this.

Power and Research

As a researcher, it was possible that I might have been conflated with the mental health system. It was important that from the outset I make it clear that any particular issues raised during the meetings would be kept confidential. This was necessary from both a research as well as an ethical point of view, since confusion about this issue might have led to an inaccurate picture emerging, or significant anger being directed at me, both situations hindering the research process. It was also important to make it clear that I could not change anything directly, and thus any specific concerns should be addressed to the appropriate people. In preparing for this situation, I tried to have as much knowledge as possible with regard to the appropriate procedures for registering specific complaints, for example against

hospitals, and to the Human Rights Commission etc.

It was also possible that the participants might have seen me as an authority on human rights issues. It was important to address this as early as possible in the research, by making it clear that I was there to learn what their views on human rights are, and, flowing from the action research orientation of the research, that we were involved in creating a joint understanding of human rights. While I discussed specific documents, it was important that I did not misrepresent myself, as this would have been unethical. The mentally ill constitute a vulnerable group, and it was important that I take all appropriate steps to ensure that I act ethically. My ethics as a researcher were informed by the ideas of action research, therefore the research had the goal of empowering the participants and benefiting them in some way.

The power dynamics between researcher and research participant become more salient when working with a vulnerable population such as that with which this study was concerned. These dynamics cannot be separated from the social context in which research takes place. I am a young, white, healthy male. The participants were black and Coloured people diagnosed with mental illness. They were all on Disability Grants, with the majority living in poorer communities characterised by high levels of gang-related violence and substance abuse. Thus, my social position immediately placed me in a more powerful position in many ways. This served to reinforce the power differential that exists between researcher and research participant. The issue of power was also particularly relevant since it is this issue around which the research revolves in many ways.

Having considered some of the ideas that informed the method and the analysis as well as giving some consideration of pertinent issues in the research process such as power, validity

and reflexivity, it is now possible to move on to an analysis of the case material.

University of Cape Town

Chapter 6

Analysis

This chapter looks at the responses of the participants to the scenarios, and the ideas that emerge around rights, the participants' sense of themselves, and the ways in which they feel other people respond to them. Some attempt is also made to give the reader a sense of the process of the research, and the way that ideas emerged from the groups, and their interaction. I have grouped the analysis into various themes.

They are:

- the interaction between identity and mental illness
- the context within which they make sense of their rights
- the ways in which rights are defined for people diagnosed with mental illness

Ordering the analysis around these themes does have the effect of breaking up what was a flow of ideas and a negotiation of various viewpoints. However, it was necessary in order to make sense of the material.

The Workshop Process

In order to counter the effect of breaking up the flow of ideas, which has the effect of disrupting the feeling of how the meetings involved negotiation of meaning, it would be useful to provide some sense of the process of each group. The first group consisted of three male and two female participants, all of whom were Coloured. The discussion started somewhat slowly, particularly as I had initially planned for there to be seven participants, although only five arrived on the day. The participants were to some extent unreliable, and I was forced to stress the times of the meetings. At different stages, two of the participants in

the first group got short-term jobs, which meant that they did not arrive for the workshops. As the meetings progressed, and participants became more familiar with each other and myself, more information was shared. Robert was somewhat disruptive, since relative to the other group members, he showed more symptoms of his illness, at times finding it difficult to follow the discussion. This also led to him including explanations of things which were somewhat tangential. What is interesting is that at such times, the other group members and myself became exasperated and tried to continue with our discussions, ignoring Robert. This suggests something of the experience of having one's views ignored, which participants identified as a response to mental illness on the part of other people. It was difficult to try and keep the discussion focussed while keeping to my stated intention of allowing everyone the space to participate. However, Robert's input did lead to questions and discussion, and in this way was at time quite useful for eliciting ideas that may have been missed otherwise. The slow start of the discussions also meant that I asked more questions initially, and only later did I let the discussion flow more.

The second group consisted solely of female participants. This may have led to what I felt to be one of the most significant differences between the two groups. The second group took on a more supportive character, with participants supporting each other. I was also more confident to let discussion flow, and so daily tribulations also became part of the subject matter discussed. This fitted in with the research ethos of letting participants shape the course of the research process. It also allowed an insight into some of the issues that participants framed as rights issues and asked me for my opinion on.

As would be expected in this kind of group, there was seldom seamless agreement over the participants' views. One example was the debate over whether to disclose one's status as a

person diagnosed with a mental illness in an interview or employment situation. Some participants felt that it was acceptable not to let a potential employer know that one was being treated for a mental illness, because of the likelihood that they would not hire you, and the individual might be desperate for the job. Others felt that it was better to be honest from the beginning. The first group did not reach a consensus on this issue, but the second group felt that a failure to disclose would mean that potential employers would continue in their ignorance about mental illness. It was felt that if a person in that situation could make an employer understand that they were the same as any other person, then this would benefit all people diagnosed with a mental illness. This is one example where ideas were negotiated. I had stressed at the start of each group that there was a need to respect each other's viewpoint, and there was no argument about this issue. Rather, participants tried to negotiate, and where consensus was unlikely, agreed that it would depend on the individual's reading of the situation, and their own feelings at the time. This response in itself suggested the desire not to be overly prescriptive for other people diagnosed with mental illnesses. This was one example of the negotiation between group members, and there were others, some of which are noted below.

Both sets of participants indicated that they had enjoyed the sessions, and felt that they had learnt a lot. There was a sense of catharsis after some of the sessions, particularly where scenarios had touched on problematic issues in people's lives, such as session three's discussion of personal relationships. The final session was aimed at rounding off what had been discussed, and in these sessions, there was the sense that ideas had been largely agreed upon. These sessions focussed on trying to come up with advice for other people in similar situations to those discussed in the scenario's as well as bringing in more general ideas about rights which had been discussed. The group members seemed to become closer to each other,

and even where certain members had personal problems with each other, there was a sense that the necessity for tolerance was understood. Group dynamics clearly also played a part in the emergence of understandings, since there were understandings of each other as well as of the subject matter.

Analysis of the Discussions

Identity and Mental Illness

Under this theme, I look at participants' experience of coming to terms with their diagnosis and the ways in which they attempt to negotiate the meaning of mental illness.

Coming to terms with the diagnosis

I begin this section with an examination of participants' responses to their diagnosis. Participants described a lack of awareness about mental illness in the community, which had an impact on the way they had dealt with their diagnosis. Overall, there seems to be a clear struggle to negotiate an identity, integrating the diagnosis as well as the reactions of others into one's sense of self.

In Group Two's second workshop, Jean said: "I never thought that it would happen to me, but it happened to me. It can happen to anyone." Earlier in the same session, Daphne described how she felt on her first diagnosis: "Its difficult for a person...the very first time...its like a shock going through you." In a later session, Jean suggested a potential positive response to the diagnosis, which comes from acceptance:

We focus a lot on the labeling and the stigma...I felt personally, I don't want people to still reject me, although I sit with this problem, I suffer from a mental illness, and before I was in total denial. But I've accepted that I do suffer from a mental illness

and the fact that I know that I'm suffering, I can be there for people that's also suffering.

In contrast, Maria was quite glad to be admitted to hospital, because she felt that then she started to understand what was happening to her:

I was very happy when they admitted me because I didn't know what was going on and the doctor told me I've got this illness. And I was shocked because I didn't know that it can happen to me. And why did it happen...I was so unhappy about it.

In Group One's first session, Ebrahim attempted to explain the effect of mental illness on one's identity:

Well, I think um, I mean, when you go through this process of being a patient, you ... tend to lose a lot of things within yourself, your resources, what you are ...capable ... of doing. You lost some of your identity things.

Ebrahim conveys the idea that there is a process involved in coming to terms with your illness. Leanne elaborated on the issue of identity and mental illness in a later session: "Part of saying who you are and what you are about is saying this is part of me (the mental illness). (Yet) you are not the diagnosis." What seems to come across from this excerpt is that the diagnosis is part but not the whole of who the person is.

Sophia explained that you "just have to accept that I've got to get used to it."

But this did come at a cost, as Sophia explained in the second meeting of Group Two: "You feel different...how can I say it...you're not a normal person...you feel like you let yourself down, you think less of yourself as a person."

In some of these comments, there is the sense that mental illness is integral to a felt sense of who the participants are. There is also the idea that they had to go through a distressing

process in coming to terms with their new identity. On the other hand, they seemed to feel a need to reject the idea, to say that 'I am not my illness'. In rejecting the idea that they 'are' their illness, participants seemed to be rejecting other people's perceptions of them. There may also be the added complexity of not always being actively psychotic, or experiencing subjective discomfort due to illness, which creates uncertainty for them about who they are. And yet the medication reinforces the idea that the person is ill.

Although there seems to be a degree of assertiveness in the accounts of the experience of mental illness, the participants seemed less confident when discussing how they presented themselves to others. There was a feeling that at times, it was better to hide the fact that they had a mental illness from others. This seemed to be an experience that the participants were familiar with. Sophia identified with the need to hide the symptoms of the illness, saying in Group Two's second session: "If I've got symptoms...then I don't tell anyone about it." In the next session, Maria explained how this contributed to feelings of isolation:

And in my area there where I stay in the Eastern Cape, I don't know who's the other people that's got schizophrenia or that's got the depression or bipolar. I just know its myself; I'm the only one. Because they don't talk it, they don't...understand it.

In the same group's second session, Florence linked hiding the illness to a lack of acceptance of one's own illness: "There are so many people suffering from this mental illness, that can't accept the fact that they are mentally ill. So they like to isolate themselves." In the same session, Daphne identified this as a potential reason for non-compliance with medication: "Why don't they want to take their medication. Because they don't want to be classified with those that are on medication. ...They feel they'd rather withdraw themselves, and keep everything to themselves." This was one of many references to medication during the meetings. Medication seemed to play a role in establishing the participants' identity as 'ill'.

Ben's comments in the first group's first session suggest an alternative interpretation to Florence's idea that the problem lies with individuals not accepting their own diagnosis. He says that it had more to do with others not accepting the person diagnosed with a mental illness, which led to people not revealing their illness.

Ben: But it was always my story to tell them: "No um I told the doctor I don't know what I'm doing in here", that was always my story.

Davyd: Why did you, why did you say that?

Ben: To fit in with my friends so they don't make fun of me.

This issue was not resolved in either of the groups, because it was felt that it depended on the individual, and the circumstance as to whether or not the illness was revealed. The issue is complicated by other factors. In the first session, Group One identified an economic imperative to hiding the illness. In a job interview, some of the participants felt it would be acceptable to hide one's illness from the employer, at least until one was given the job. Ebrahim said: "Well, I um when went for jobs, I was working after my nervous breakdown. I went to work right, and I didn't tell them about my illness." And later Leanne said: "Um, I've never been in the workplace situation so I don't know but I personally don't feel that to start with it, you need to give your full story."

The issue seemed to be quite complex, and touched on the issue of rights, because it was felt that disclosing one's status should not make a difference to how people treated you. This suggests that there was the sense that a person had a right to be treated a certain way, irrespective of their mental health status. In the same session, I asked if someone in an employment situation should tell a potential employer that they have been diagnosed with a mental illness. Ebrahim said that they should. I sought clarification from the group, to which

Ben replied: “Yes, he’s got to stand up for his right. His right allows him to stand against the boss.” He went on to say: “Make it clear that he should be given a chance. He’s got the qualifications; he’s got the experience. What else do they want?” Ben’s comment seems to illustrate his feelings of frustration. These comments also suggest that the idea of hiding the illness is not altogether straightforward.

In spite of this, there was a strong sense that the illness must be hidden, that the person must try and appear ‘normal.’ This is likely to be a function of the strong reactions which mental illness evokes in the community. It may also be linked to the lack of understanding about mental illness that participants identified on the part of other people. One of the strongest ideas to emerge from the workshops was the need to educate society about mental illness. Thus, the need to keep their illness hidden had to be balanced with the desire to speak out, and assert one’s rights. This position is an ambiguous one, since there may be negative consequences for the person who stands up for him/herself. What comes across in this issue is the idea that participants did not necessarily experience themselves as being ‘wrong’ in some fundamental way, but they had the expectation that other people found them unacceptable. This echoes Watermeyer’s (2000) claim that aspects of the disability experience are unacceptable to ‘normal’ people, and that experience is consequently rendered invisible. In Group One’s first meeting, Ebrahim said, “I think people need to be more educated yes.” Jean agreed, “We need to educate them yes.”

Ebrahim: We need to educate them, they need to be educated.

Jean: We have to make aware, yes we have to make them aware that actually you know.

Ben: That’s what CCAB must do.

Jean: And this is an ongoing thing this, I mean this is something that's not going to change overnight...you know, that stigma is still going to take some time, for people, but you, but you must educate people all the time.

This discussion was echoed in the other group by Sophia: "I'm proud of myself because... I can educate people." The participants recognised that hiding the illness was ultimately not beneficial to them, because it maintained the status quo. Rather, they suggested that by revealing the fact that they had been diagnosed with mental illness, and being open, they could educate others about the realities of mental illness, and challenge some of the misconceptions that underpinned the stigma associated with mental illness. However, it was also recognised that having to explain oneself to others all the time was draining, and that they could not be prescriptive about this issue.

Some participants said that they preferred the company of other mentally ill people. While participants stressed that this was because they share similar understandings and experiences, it could also be seen as a form of hiding the illness, by not having to explain one-self at every juncture to others. Robert's comments in the second workshop imply a sense of shared trauma, of being a survivor: "The best people who are genuine to you are the people you were in hospital with because it's a sad thing." Jean agreed, "Yes, because they know, you speak the same language, they know exactly. You don't need to explain to them in detail." Later during the same exchange, Jean touched on this issue again: "You need to explain yourself to other people all the time. And it's so tiring."

It seems that participants recognised their own struggle to come to terms with their diagnosis. This was however by what they perceived as the negative reactions of others. They felt, on the one hand, that they should be able to speak openly about their illness, but on the other

hand that they needed to keep the illness hidden in the face of potential prejudice. Some participants suggested that they preferred the company of other people with mental illness, as this relieved them of the burden of having to constantly account for themselves.

The meaning of mental illness

The reactions of participants to their diagnosis suggested something of the way their identity had been altered by being diagnosed with a mental illness and how they attempted to negotiate this new identity for themselves. However, there was some debate over exactly how being diagnosed with a mental illness affected the person's sense of who they are. This debate was present from the very first workshop, and the ideas that seemed to underlie the different claims were present in some way throughout the course of the workshops.

The first response from participants was that mental illness was the same as any other illness. This was something that the majority of participants seemed to agree on, although there were diverging views, and different ways of expressing the idea. Jean felt that someone diagnosed with a mental illness was no different from anyone else. As she said: "People don't realise that mental illness is an illness just like any other illnesses, you know. I mean you can get through it and you can live a normal life."

However, Leanne disagreed with her. Leanne: I think um saying that its an illness just like high cholesterol or high blood pressure, I think that's a simple way of saying that to categorise it. But I think mental illness affects far more than what diabetes will affect you.

Jean: But it's an illness

Leanne agreed that it was an illness, but felt that the issue was more complex than Jean might be prepared to admit. She went on to say:

Yes, it is an illness. But diabetes is going to say to you, you must change your diet. Um mental illness affects far more factors in your life, I mean it affects you more, your personality, your relationships with people, it affects your work, your performance at work, it affects your, it even affects your eating habits as well. Your social life, it affects far more things, so for to actually categorise it with...the other...illnesses is not, is not really saying exactly what its, you know what its about and how deep it goes.

Members made these comments in Group One's first session. The group context allowed the space for negotiation between these two positions. The second group was more open to Jean's position. It is clear that the participants' responses reflect two political positions, in a sense. Jean's response aims to normalise her experience. This seems to be a common response on the part of the participants, an attempt to assert that the person with a mental illness is not different from others. This ties in with the idea, from the literature (see Chapter 3 and 4) that assertions of difference are tied to assertions of diminished worth. By claiming that mental illness is the same as any other illness, Jean is claiming that she is not different and therefore of equal worth to others. This idea of worth comes across as something central to negotiations of identity in relation to mental illness, as well as to the role rights play, in arguing for the 'worth' of the rights-bearer. Leanne's argument is that, viewing the illness as any other illness may lead to inadequate attention being devoted to the realities of the impairment. This echoes some of the writings on disability (French, 1993). The participants came back to this issue in various guises, and there was never really a resolution.

In Group Two's third session, Florence suggested that: "Mental illness is like any other illness (because) it can be controlled by medication", to which Jean responded: "medication

and psychotherapy". Florence's comment reflects something of the concern for controllability, which again reaffirms the similarity of the mentally ill person to other physically ill people, and may tie into other issues that are associated with medication. Several participants, in both groups repeated the assertion that the illness is the same as any other. It seems to function as a sort of reassurance - it was linked to the idea that it could be controlled in much the same way as a physical illness, with, as Jean put it: "medication and psychotherapy." One reason for this attitude seems to underlie Robert's comment in Group One's second session: "Its only a problem he's (the doctor's) treating". Robert's comment suggests that if it is an illness, then the person is not 'wrong' or 'bad', yet it is merely the illness that makes them act strange. This is linked to the next strategy for dealing with the illness.

When participants discussed the periods when they are suffering from the symptoms of the illness, or more particularly when they exhibit psychotic symptoms, they often used the idea that they were not themselves. For example, in discussing an incident in which she attacked her nephew, and beat the child quite badly, Sophia said that she was not herself, and Jean concurred. The mother of the child has only recently started speaking to Sophia after several years, and the incident was a traumatic one for all concerned. This suggests that others do not necessarily make this differentiation between the person when sick and the person when well. The following exchange occurred during Group Two's fourth session.

Jean: But Sophia, you not responsible for what happened.

Sophia: She said to me "you a child-killer, you almost killed my child". And from that day on, nobody trusts me with their children.

This suggests some of the lasting effects of such an incident on the relationships of the person diagnosed with a mental illness and others. The family won't leave Sophia alone with the

children “and they won’t tell me why” but she knows it’s because of the incident. Sophia went on to say: “I love children...I wasn’t myself that day... I only realised when the child landed up in hospital.” These issues tie into what the literature seems to suggest is a strong concern on the part of others for the potential dangerousness of people diagnosed with mental illness (see Prins, 1999 for a discussion). This exchange shows that the issue is complex, because the person with a mental illness may in fact have the potential to act dangerously, and struggle to reconcile this with their sense of themselves, as non-violent when not ill. Behaving violently also would be likely to reinforce the perception on the part of others that people diagnosed with mental illnesses are dangerous.

In the same session, Jean talked about an experience she had as a pre-school teacher. She said: “The doctor told me I won’t be able to work with children anymore, so I took it out on one of the children.” Later, Sophia sought to offer some justification or explanation for her experience, saying: “The doctors told me that mental patients become, they become jealous. But that wasn’t what happened to me.” Here, however, she rejects the potential cause offered by a doctor. Yet she was unable to explain why she had acted that way. Daphne tried to give some explanation: “At that moment, when you doing that stuff, you don’t realise”

In the other group’s second session, Leanne had offered some insight into the effect of displaying symptoms of mental illness while in the community.

People remember you in your...manic state and then they will think that “Well I couldn’t communicate with you fully while you were manic, so I probably still can’t, even though you seem so much better...so I’ll speak to someone else, to get the message across.”

Here, it seems that while the participants may have viewed the actions being carried out by

the 'sick selves' as being performed at a time when they are "not themselves", it seems others do not share this view. Something similar appears to have happened in Sophia's incident with her nephew. Consequently, the sick and well selves are seen as the same, and people tend to treat the person diagnosed with a mental illness as permanently unwell, disabled, or dangerous, as some of these examples suggest. However, the participants seemed to try to distance themselves from their actions when they are sick. This could be interpreted as a recognition of the stigma associated with mental illness, which is seen as a 'badness' which is imputed to the person diagnosed with the mental illness. But it seems clear that the participants did not want to be seen as 'bad' and indeed did not see themselves as 'bad' hence they split their well and sick selves.

The issue of madness and how it related to mental illness was something which came up quite a bit in the discussions. For example in Group Two's third session, Daphne talked about a particular conversation on the topic of madness. She said:

Last night the topic came out about 'mad' and I said there isn't existing mad people. To me, there isn't people that's mad, the word mad don't exist to me. Because I feel, we that are in this situation, we are not mad. We're mentally disturbed. But you don't get mad people.

Jean responded by saying: "It takes a big mad one to recognise a small mad one." Here, Jean suggests that it is not the person with a mental illness that is mad, but the other 'normal' person. Daphne went on to say: "So I told him *ek issie mal, jy's mal want een mal mens* recognise *die ander mal mens*." (I'm not mad because one mad person recognises another.) In her response, Jean displayed some resignation to this state of affairs: "I don't get cross anymore when people label me as mad. It just shows me they have very little insight."

This extract suggests something of the negative connotations participants associated with the idea of madness, and the fear that they would be labeled in this way. None of the participants identified themselves as 'mad' and said that the use of this label showed a lack of insight on the part of others. As Maria said "they don't understand about mental illness". What struck me about this and similar exchanges was the reference to insight. 'A lack of insight' is a phrase often used by psychiatrists to describe those in an active phase of a psychotic mental illness, suggesting that they do not understand that they are ill. From a discursive point of view, it is interesting to note how this labeling has to an extent been turned around, and applied to those who would seek to apply labels to those diagnosed with mental illness.

The participants described how the psychiatric institution was also associated with the label of madness, to the point that it seems the merest mention of a well-known institution evoked a response from other people. In discussing the first scenario (see Appendix), Maria identified the link people make between the institution and 'madness'. She said: "Maybe the boss thinks that John is becoming mad sometimes, because he thinks Valkenberg hospital is for the mad people." Florence also suggested that this was a common response to her experience:

Well that's what my relatives told me. "What am I doing in a mad place, a mental institution?" Well then honestly I didn't know about it, I knew nothing about mental illness. I was also like very upset when they asked me, "What are you doing in a mad hospital?" But ever since I got ill, I was just thinking about this mental illness, not about madness, its nothing to do with madness. Even I can always say, "Don't get mad" to Maria then she will think okay, its 'cause I'm mentally ill, that's why I said don't be mad, whatever.

In Group Two's third session, Maria reflected on her response to being labeled as 'mad': "And it doesn't sound nice, because you know at that time that you are not mad, you've got a mental illness." Florence agreed: "Its very difficult to understand that word 'mad'." Jean went on to say: "You use it in many situations." This discussion touches on the confusion and the difficulty that participants had in coming to terms with being labeled by others. Madness was one of the most significant themes that emerged in the discussions. There was a sense in which this idea had to be reconciled with the idea of mental illness. Overall, there was a strong sense that this was an extremely negative idea, which participants dealt with in a variety of ways, generally characterised by a rejection of this idea that *they* are the ones that are 'mad'.

One way in which participants seemed to illustrate their rejection of the label and the associated identity of 'madness' was through the attributing of 'madness' to others. This can be seen as a strategy for distancing themselves from the negative label and its implications. For example, in Group Two's second session, Sophia said: "Do you see me as mad - I don't think I'm mad. I think you've got the problem, I haven't got a problem." During this session, I was brought into this discussion as an example. Florence said, "Even Davyd, He's not suffering from a mental illness, he's got his ups and downs." Jean agreed: "Everyone does, ja."

Florence revealed a justification for this line of reasoning: "Even those people that's out there, they can say ja, you're mad or you're suffering from a mental illness. They go to private psychiatrists, with the same problems...they also take medication."

Here, the reality that people who can afford private psychiatrists prefer to go and see them is used to justify the belief that people 'out there' (i.e. the ones doing the labeling) are also suffering from mental illnesses. In so doing, the act of labeling becomes a function of wealth

rather than mental health status.

In Group Two's third session, Maria suggested that the situation was worse for people living in townships.

Ja, I feel sad when my friends tell me, my friends who stay in the townships, when they come and say, "Hoo, in the townships they take me mad and they take me as a mad person, they give me names when I'm walking on the street, and they give me names," and that and that. I feel sad about that, I don't know. How can we help it?

This excerpt also reflects some resignation with regard to improving the situation. Florence's remark that mental illness "is nothing to do with madness" captures the idea of a rejection of this label. This discussion showed something of the struggle and negotiation of a position or a label which others try to apply to the participants, and which the participants seek to reject. In general, Maria felt that the situation was worse in Xhosa-speaking, or traditional societies. She said:

That's why...they say you've got *amafufunyana*, that's because they don't know what is it...ja, and they say we are bewitched, you know...they don't understand about it, and its going to be difficult for me, if I can go back there (to the Eastern Cape). Because if I go back there and I'm sick the other day and they take me to Grahamstown...they will tell me I'm a mad person.

Florence agreed: "No, its very difficult in our culture because they just like send you to witch doctors, you go off and...then treat you as a mad person. If you make a mistake, 'Oh, its mad, what can you do?'" The participants made the point that, in Xhosa, there was no word for 'mental illness'. Rather, the word that was used had the same meaning as 'madness.' This suggests that even the opportunity to reframe their experience in terms of an illness, which

other participants sought to do, was not available to people speaking Xhosa. The complex relationship between identity, labels and language is suggested here, because Florence nevertheless asserts that mental illness “is nothing to do with madness.”

Another strategy which participants revealed was the tendency to stress that mental illness could affect anyone. In Group Two’s second session, Jean said: “I never thought that it would happen to me, but it happened to me.... It can happen to anyone.” Later, Florence said: “There are so many people suffering from this mental illness, that can’t accept the fact that they are mentally ill. So they like to isolate themselves.” Maria agreed: “Look at Fountain House, there are people with degrees and everything, they are in these programs.” To which Florence replied: “I was in Valkenberg together with a psychiatrist.” In the other group, Ebrahim had said in the first session: “According to statistics, there was a World Health thing here at UCT to discuss that, how mental illness is second to AIDS according to people. It’s increasing everyday, the cases are increasing everyday.” These comments suggest an attempt to ‘normalise’ the illness, and classifying it as an illness not as madness is related to this. There seems to be a distinction between madness as something fundamentally wrong with the person, and mental illness, which participants related either to upbringing or a physical disposition. As Florence said: “You’re suffering from a mental illness because of your background, you see.” Leanne on the other hand said that: “It’s your make-up.” What seems clear is that madness is something fundamental to the identity of the person, and is perforce negative. Thus, to accept the label of ‘mad’ is to accept a negative identity, a negative perception of oneself. It is this which participants seemed to be rejecting by rejecting the label. This contrasts with the idea of an ‘internalised oppression’ (see Bartky, 1990; Fanon, 1967:1993), in which people are passive and powerless to challenge the labeling and their positioning by society. There was a sense in which the participants refused to be positioned

by others, instead attempting to forge their own understanding of themselves and their illness.

Summary

What these ideas suggest is that participants seem to try and assert themselves as reasonable people, as being like any other person. To do this, there is a need to reject, and withstand, the pejorative labeling of others. There thus appeared to be a strategy amongst the participants aimed at rejecting the label of madness, which denotes difference. There was also an attempt to draw attention to the widespread nature of mental illness, and the fact that it can affect anyone. My suggestion is that there is an attempt on the part of the participants to challenge the idea that they are inherently flawed, as people. This returns to the idea of worth, since it seems that there is an attempt to assert their worth through denying that they are different from others. In some way this seems fundamental to our discussions on human rights. Throughout the discussions, in both groups, the idea of worth was central. Human rights are a testament to the inherent worth of the rights-bearer, because as a person with rights, there is a duty imposed on others to protect those rights and consequently to protect that individual (Strong, 1980). This labeling is to an extent informed by social conceptions of what mental illness is, and what people diagnosed with mental illness are like. The need to assert oneself, and stand up for one's rights plays a part in everyday social interactions. What can be seen is that, in this context, doubt creeps in, with participants at times feeling the need to hide the illness. This decision to hide one's diagnosis is often a function of very pragmatic concerns, such as the need to work and earn money to support oneself. The reliance on medication in this context becomes a pivotal issue, situating the person as someone in need of care. The effect of this is to undermine the person's sense of their own autonomy.

The Context of Negotiating Rights

The next major theme was the context within which participants' negotiated their rights. This involved examining issues centred on treatment for mental illness, in both the institution and the community, as well as the participants' interactions with the wider community. The participants' discussions seemed to suggest that the societal response, as manifest in the health system, their economic situation, the family and the community, is characterised by a process of dis-empowering the person diagnosed with mental illness. This suggests something of how these contexts are experienced by people diagnosed with mental illnesses. The relevance of this for a study of rights is that these feelings of disempowerment can diminish the likelihood that rights will be claimed.

The mental health system

The mental health system, as discussed in Chapter 1, is currently shifting its emphasis towards care in the community. The implication for the study of rights is that, despite the developments in the rights of mental patients in institutions (see Chapter 2), the majority of the contact between patients and the mental health system will occur in the community. Thus, it is in this context that the rights of people diagnosed with mental illness need to be examined.

Interacting with the formal mental health system.

In general, the feeling among participants seems to be that mental health service staff are able to act in any way that they choose, and the 'patient' has very little power to object. Jean said, in Group Two's fourth session: "They (staff) don't want to be put up with you, they want to make their task easier." And Maria concurred: "They treat us different, they treat us the way we don't want." Later in the same session, Jean went on to suggest that a lack of consultation

was part of the problem. She said: "There's actually no communication between patient and staff...there's like a wall between patient and staff...you just here as a patient, we are the staff, we got a right to do what we want to do." She also felt that this situation was evident in relation to appointments: "Its not right...(that) you must just fall in with that...why can't we be part of the decision...it goes about you...why must a doctor decide." This suggests a strong sense of being disempowered by institutional practices. It is interesting that Jean frames this issue in terms of what the staff feel are their rights. It seems clear that the participants feel that it is their right to be consulted with regard to their treatment.

This issue also ties into a larger feeling, expressed succinctly by Robert in Group One's second session. This is the feeling of not being listened to and, in effect, of having one's viewpoint discounted. He said: "The psychiatrist talks all nicely to you but you don't want to hear his words now, you want him to listen to you." Robert went on to suggest something of the way the psychiatrist's power causes the service user to not object: "He can maybe take your disability grant away from you."

These ideas extend into the diagnostic procedure. In Group Two's fourth session, Jean discussed an incident in some depth in which she was trying to get her questions about her medication answered. The doctor refused to answer her, and continued preparing an injection. Jean was in a manic phase at the time, and, frustrated by the lack of response from the doctor, hit out at her. Jean was wrestled to a bed, given an injection, and woke up in another hospital. She was also concerned because the incident was recorded in her file, and she felt it was not right that now she had been noted as a 'violent' case, when she felt she was simply responding to a very frustrating situation. The comments made in Group Two's fourth session suggest the lasting effect of such an incident.

Jean: Now there's something written about you,

Sophia: That's not true,

Jean: (And) they treat you according to what's written there.

The sense that the institution was malevolent came across in some of the responses. For example, Ebrahim said during Group One's fourth workshop: "I don't know, they want to get hold of you, your inner being. In hospital, they want to get hold of your inner self and destroy what is in you, left in you." What is significant here is that the participants seem to recognise such experiences as infringements of their rights. Yet they did not seem able to act on this, and expressed frustration at their feelings of powerlessness.

There was also felt to be some discrimination at institutions and within the integrated health services. Jean said: "At some hospitals, they still do have this discrimination, where the psych patients are sitting off to one side...everyone, they see, if you're sitting in that corner, in that passage, it's just the psych patients." She expressed her desire for a situation where "it won't be so obvious. That is why I prefer coming to Valkenberg." Being treated at a community clinic also means being treated by people that are from one's own community. Some participants felt that this was unfair, since the staff then identified them at a later stage, for example at a bus stop, as Jean experienced. She said that there was the sense that the nurse who saw her on the street was pointing her out to others, identifying her as a psychiatric patient. This raises questions about the community clinic staff's commitments to the patient's right to be treated confidentially. It also underlines the interplay between the perceptions of mental illness that participants suggest exist in the community, and the treatment that the participants experienced while being treated by people from those same communities. The staff are likely to be subject to the same prejudices as other members of the community. Despite these issues, it was felt that overall, the move towards community care was a positive development. Daphne felt that the integrating of all the health services

was a positive development. She said the reason for the integration was “so we don’t feel out.” Even Jean agreed that the situation was improving, saying: “Slowly but surely, its falling into place.”

The experience seems to be largely one in which the person diagnosed with a mental illness has the experience of not being listened to, and at a more fundamental level of not being taken seriously. Critically, Robert’s comment suggests the ways in which issues of power continue to be played out in the doctor-patient relationship, with the issue of money, revealed as a central concern, reinforcing this. In the first group’s second meeting, Robert said: “He can maybe take your disability grant away from you because you’ve become aggressive. Because he’s the doctor, he’s treating you and you can’t tell him what to do”

The participants seemed to experience the mental health system as disempowering, which may make them less likely to assert their rights, because they may feel that they will not be taken seriously. There are also practical, pragmatic concerns related to money, which impinge on their ability to claim their rights, and act on their sense of injustice. The effect of not being listened to for so long is likely to be that an individual may lack the confidence to repeatedly stand up for themselves. What these comments also reveal is some sense of what are felt to be the rights of the person diagnosed with a mental illness, i.e. that they feel that they should have a right to express their concerns in relation to treatment, and be listened to by mental health service staff.

Illness and medication

Medication was something that evoked generally negative reactions. Medication seems to serve as a reminder of their status as people diagnosed with mental illness, and all that this

entails. However, the participants seemed to accept it as necessary, because it helps to control the symptoms. Medication also serves to reinforce the idea that mental illness is an illness i.e. distinct from 'madness' because it can be controlled to an extent by medication. However, participants still recognise that medication cannot totally prevent relapses.

In the first group's second meeting, Robert made a comment that captured his feelings about medication: "The things they think about you now, once you've taken these drugs, that the psychiatrist gave you, they know its gonna kill me." Ebrahim expressed a similar fear, in the fourth session: "I think our lifespan has been shortened by the medication...we need to have our rights on the medication, because our lifespan has been shortened." It is debatable whether these comments relate to a well-founded theory on the toxicity of the medications (what Pilgrim & Rogers, 1996, term "iatrogenic risk" - Pilgrim & Rogers, 1996, p. 184, see also Isaac & Armat, 1990). What I would argue is more important is the fact that they reflect a negative view of medication, a view that many of the participants seemed to share, although for varying reasons. These comments suggest that at least some of the participants see medication as something harmful, despite the fact that it helps to control the symptoms of the illness. Jean's comments reveal something of the anxiety that surrounds medication. But they also reflect what I felt was an encouraging determination to get as much information as possible from service providers, before agreeing to treatment.

Then I ask him and I didn't want to take medication and that. It really didn't make sense to me to be on all those medications. I mean, what's the worst that can happen if I don't take these meds? If I take it today and don't take it tomorrow? Until they answered all my questions and I said okay its important for me to be on this medication, to sort of keep that balance, you know, about this chemical imbalance in my brain. You know those sort of things, that's important, doctors don't realise that

they need to explain to you all these things. You know I was... I had relapses constantly because I didn't take my meds like I was supposed to because I didn't know why I should take it.

In a later session, Sophia echoed Jean's experiences, saying: "Every time I have relapse, 'cause I stop my medication." Jean acknowledged that relapses were unpredictable, despite the use of medication.

The fact that you're taking your meds doesn't mean that you're not gonna have a relapse. You still do have, because with bipolar, you still have those mood swings even if you're on medication, I still have them but its just that its better controlled now.

In her second session, Daphne suggested another reason for a failure to take medication, in addition to Jean's idea that medication was not taken because it was not fully understood. She said: "Why don't they want to take their medication. Because they don't want to be classified with those that are on medication. They feel they'd rather withdraw themselves, and keep everything to themselves." This suggests something of the way that medication is intimately connected to one's identity as a person with a mental illness. Florence joked about the medication in Group Two's fourth meeting, but her comments seem to indicate some underlying anxiety, and capture the sense of resignation that stems from the fact that most mental illnesses are not curable. She said: "Your whole life in prison... because your body's already used to the medication, so you can't stop taking it." Sophia echoed this sense of frustration:

I don't want to be on medication for the rest of my life, I want to get off...not to depend on it all the time. I want to live a normal life; I want to be just like somebody

else...I don't want to suffer from a mental illness anymore.

Jean laughed and Sophia asked why she was laughing. Jean replied: "I'm not laughing at you, I'm laughing with you." Here, the shared frustration is clearly evident behind the humour. Sophia's comments also suggest something of the way medication is associated with the sense of difference, in that having to take medication is a reminder of the illness and thus a reminder of the fact that one is different. The rejection of medication underpins the longing to 'be normal' and "live a normal life". In another session, Robert seemed to suggest something of the way medication reinforced the sense of difference, saying: "This medication the doctor's giving me, it hurts me too, because I can't face (other people) anymore." Jean also expressed her frustration in Group Two's fifth session:

You feel at times like just quitting everything, giving up medication and wasting your time and all that because what is it...even if you on medication, you still have relapses and all those things, so what, I mean for me sometimes it doesn't make sense to be on all this chemicals that I'm taking.

However, as much as medication seems to be viewed as confirming their 'difference', it is also viewed as necessary. There is almost a sense in which this is part of the bargain: if those with mental illnesses take their medication, they should be treated as 'normal' people.

Daphne's comments in the first session of Group Two seem to suggest this

Its not right that they don't give you the job because um you got the experience and you can do the job, its just that you must stay on your medication. That's very important, you must stay on your medication, and um they should give you, they should give us, that are mentally ill, they should give us the chance in life, to prove ourself, we can do it.

The issue of medication also came across as something that other people focussed on. There seems to be the situation in which people are constantly checking up on the person, making sure that they have taken their medication. Robert discussed it in session one, in the work environment: "Well the boss started having meetings and he said 'why didn't you drink your pills' because I was just quiet all the time."

And later he said: "And these people came with arguments, they said, 'Why didn't you take your pills' and uh so I said, 'Yes I did take my pills'." In session four, Ebrahim suggested a similar situation existed at home: "When you at home...my mom calls me, tells me 'take your tablets'. Also reminds you if you are getting, not aggressive, but if you are defending your rights, they ask you, 'Did you take your medication?'" This last comment suggest the ways in which the medication issue forms part of an understanding of the application of rights in the context of mental illness. In particular, it suggests that medication is used to undermine what may be legitimate claims by reaffirming the person's status as someone diagnosed with a mental illness, suggesting the way in which medication is linked to issues of identity. This issue becomes increasingly salient when people are being treated in the community.

Also central to this are issues around the right to make choices about medication. In the same meeting, Robert talked about the situation in the institution: "That's why, when I was in hospital, and I started getting drunk with the pills, and I didn't want to take it, so I threw it away, and I nearly got beaten up." Jean also made a comment in that meeting which tied into the idea that the commonly held view among psychiatric institution staff is that patients lack insight. She said: "They (staff) think you don't know what's happening, what's going on around you." This issue was debated, and both sides of the argument have merit. Leanne responded to Jean's comment, saying: "I think a lot of the time is when you actually psychotic, when you going to be convincing them that you don't need medication. Then they

feel it's their duty to give you, to get you down from there." Jean disagreed, replying:

Not necessarily, look it might happen Leanne,...there's many times, at the community services, like the hospitals, day hospitals, then the GP's don't really give you a chance to sort of explain...they not gonna listen to what I've got to say...they gonna just follow what's on that referral

Later, Jean expressed her frustration at the situation:

That is when this comes in where the patient just stops their medication and do her own thing. ... instead of listening to what you got to say. Like, we don't have the chance, always,...why can't they just listen to you?

In general, it seems that the issue of medication is related to the participants' identity as people diagnosed with mental illness. The experience of other people paying attention to their medications, as well as their own responses to the medication serve to highlight the link between medication and identity. It also is an issue that forms the link between their lives in the community and the mental health system. In some sense, this is the reason for the link between medication and identity, because in a very real sense, despite being outside the physical context of the institution, participants seem to feel that they are still constrained by the institution. They carry it with them in the form of medication, a regular reminder of their diagnosis.

Other forms of treatment

It was not just the biomedical form of treatment that arose in the discussions. Some participants indicated that they had experienced other forms of treatment, such as traditional methods or indigenous healing, as well as faith healing. Swartz (1998) suggests that these forms of treatment are widely made use of in South Africa, and it is necessary to briefly

consider some of the discussion that arose around this issue during the course of the discussions.

The experience with traditional healing was extremely negative in Maria's case.

She said: "They took me to the sangoma's, and I was ill-treated there, they give me muti and everything, beating me and everything, it was terrible." She went on to say: " They give you medicines to make you vomit...and its itchy." Maria also said, "You can't say anything." She felt powerless to object to her family's insistence on the use of a traditional healer, and also powerless to object to the types of treatment she received there. Maria went on to describe how her family was instructed by the sangoma to beat her, and this situation persists whenever she has a relapse. This is in stark contrast to the idea that the family should play a supportive, nurturing role in the person's recovery. Such abuse comes at a time when "you didn't know whether you were coming or going" (Jean) and was felt to actually make the person worse. Maria went on to explain that her family did not seem to bear her any ill will. Her mother was interested in the psychiatrist's perspective on mental illness, and had attended a meeting at which Maria's illness was explained. Maria said that since that time, her mother had treated her better. Yet she still worried about returning to the Eastern Cape, as her other family members still did not understand.

Traditional responses to mental illness are based on a particular view of mental illness. As Florence explained it, the traditional view is that it is often a family member that has caused the person to become mentally ill, through the use of *muti*. Thus, the illness has its cause rooted in traditional belief systems and consequently should be dealt with using traditional methods. This issue also ties into the fact that there is no word for 'mental illness' in Xhosa. The word used was translated by participants to mean 'mad,' and ties in with the particular

view of mental illness which the participants identified with the Xhosa world-view.

Faith healing is another form of treatment which came up in the discussions.

Sophia said: "My parents, they not very happy when I'm in hospital... they rather want to hang around me, they rather want me to be at home so they can take care of me." She explained that: "They very religious people so they believe in prayer."

Florence said that she had a similar experience, with people trying to help her using prayer, and her explanation gives an idea of how she integrated her faith into her understanding of the illness. She said:

They will always ask me, 'Do you believe that God can help you with your illness' and I always say, 'Okay, yes, I do believe.' But...it doesn't matter...for now, it's his choice why I have to go through this. I've accepted it.

The purpose of highlighting these other forms of treatment is to suggest some of the ways that it is not merely the medical model which is involved in people's understandings of their experience, and their response to that illness. These issues also highlight the way that cultural beliefs exert an impact on people diagnosed with mental illness. The way these factors inform and interact with one another is exceedingly complex, and as suggested by Maria's example, also have a potentially negative impact on the practice of rights. However, in Sophia's case, her family's beliefs seem to have helped her to come to terms with her diagnosis. This suggests the possibility that belief and treatment systems may be helpful in the mentally ill person's search for identity.

Economic status

Many of the participants reflected a strong desire to earn money on their own, because this

brought greater independence. This highlights the way social factors such as wealth reinforce the disempowerment of those diagnosed with mental illness. It also suggests something of the way financial concerns affect self-esteem. Robert captured this experience in Group One's second workshop: "My whole life has been brought down to...570 (Rand) a month."

The first scenario evoked strong reaction around the issue of employment and money, such as this comment from Ben:

They told me that it won't work out, with me suffering from schizophrenia. And I want the job but I just gave up and thought well, I'll just carry on with my disability grant and I mean, if I want to take a girl one day, I want to support her. I don't want she to support me, you see.

In the second group's fourth session, Sophia captured the sense of dependency that a lack of employment and money facilitated: "I don't want to depend on a grant anymore, I want to work for my own money...you appreciate what you work for."

This issue lends Florence's comment an added poignancy: "We might still stay in poverty, but we've got our rights". What comes through in these comments is the sense that the participants have a sense of what their rights are, but may feel unable to actualise these rights in the context of the dynamic interaction between social and economic factors.

Many responses touched on the existence of stigma. For example, in the first workshop, Ben said:

Like I know this guy that works and he's got TB but the boss is not worried about his illness so long as he does his job and takes his tablets. But ... I think that the mental illness has more of a stigma attached to it than any, all the other illnesses.

Stigma also had an impact on employment opportunities, as Leanne suggested in the first session:

The stigma says that... once you hear that the person is mentally ill, your going to terminate the interview, you're not going to go further. Not knowing that I can do the job better than someone that's not, that has no mental illness.

She went on to say: "At the moment it seems as though the stigma is stopping employers from giving, giving people a chance." In the same session, Leanne suggested that people recognised that the stigma was unacceptable, because they sought to rationalise it:

People find ways to substantiate why they won't employ you because they realise that routes in which they can say, "Look you can't have the job"...they just ignorant, they have the stigma attached to psychiatry so they not prepared to actually give you a chance.

The issue of hiding the illness came through in the discussions related to mental illness and employment. Some people felt the need to hide their illness, in order to get a job. In discussing a friend of hers, Florence said, in the first meeting of Group Two: "Every time he goes to work, he wants a job, he never tells the people or the, his boss, that he's suffering from a mental illness." Leanne expressed a similar idea in Group One's first session:

Most of the time, one is desperate to get the job so, you know, you're first going to see how far you can get without mentioning it. But um if you're in a situation, where you're filling out a form before you're even interviewed and they ask you about your health status, then its over before your even interviewed, because you've mentioned it there.

Her suggestion that "its over before your even interviewed" suggests something of the negative response which participants expected in the search for a job. Interestingly, the

medical staff can also play a role in encouraging people diagnosed with mental illness to hide their illness. Maria's comments also reflect the expectation of failure evident in Leanne's comments above:

The doctor, the psychiatrist told me that I mustn't tell them. But I want, I told him, I told that psychiatrist that I tell that boss, or that person that I'm looking for the job, so that he can know me and he's the doctor told me, "No, don't tell them, because you won't get the job."

Yet, hiding the illness was not always advisable in the employment situation. It may even be grounds for being dismissed. Florence mentioned another friend of hers in the first session:

She went back to the hospital, to the mental hospital.... And when um the boss found out, they dismissed her from the job. Why? Because she never said that she was mentally ill. And then she told him that, "Well, you never asked if I was mentally ill."

It was also suggested that hiding the illness in the long term was not always possible. Maria said: "We better tell them, because they're going to find out sometime." Ben suggested one way that the employer might find out.

He would like to know where you're going every month, you're taking a day off for your medication. I mean, you can't tell them your going to a dental appointment every month 'cause you need papers to prove that you were there.

What these comments suggest is that attitudes towards mental illness play a role in the employment context. What happens in this context has a direct bearing on the economic status of people diagnosed with mental illness, influencing the creation of dependency. These issues also seem to impact on the participants' sense of themselves as people able to stand up and claim their rights, as practical economic concerns may at times over-ride the desire to stand up for one's rights.

Family and Close Relationships

The family also contributes to the situation in which those diagnosed with mental illness have their views discounted and challenged, or even ignored. The medication issue and the way money disempowers people are also evident in the way some families treat those members diagnosed with a mental illness. In session two, Robert explained: "I got a problem there at home, they won't give me a cigarette, because every cent has been counted."

And it seems that this situation was something unique to those members of the family who have been diagnosed with a mental illness. As Jean said in the same session: "Everyone else could help themselves, but when it comes to me, I must ask. And yet when it comes to my disability grant, they just do what they want to." Robert and Ben agreed with this. Robert went on to suggest that his concerns were ignored, at the very least: "You just have to keep quiet again." This issue raises questions over a sense of entitlement - it is clear that the individual's have a sense that they should be entitled to do the same as other people, yet the reality is that they are often thwarted in this regard. Jean said later: "The family, they not using the money (from the Disability Grant) on you, I mean, you get the small change. In my case it was like that for a couple of years."

It seems possible that the family does not ever view the person as having fully regained their capacity to make rational decisions. The participants seemed to suggest that they were treated as if they were stupid or as if they were children. This comment from Jean gave a clear example of this: "As far as the family's concerned, you don't have a brain, they have brains, but you don't have one." Jean suggested something of the anger that this situation evokes in the person: "I'm not a child, I'm an adult. Why can't I have things when I want it?" Her comment also touches on issues of dependency, since it seems that the family view her as a

child, and reinforce this sense through their actions, which imply she cannot have the responsibility to do things for herself. As Robert said later in the second meeting: “Your family doesn’t know how to react towards you.”

It seems clear that there is some misunderstanding in families over mental illness, which spills into maltreatment. Maria explained: “Also, I suffered for a long time, before I was actually getting treatment because our families...they didn’t realise that you’re suffering and all that.” Florence elaborated:

Ja, because you still get families that don’t want to accept this illness, and they reject their children, they neglect them because they don’t understand what this thing is all about...and its because of them that we are in this nonsense.

Jean had said something similar in an earlier session: “My family said to me, ‘They don’t have mad people in their family, they don’t know where I’m coming from’...They still saying things like that.” This suggests the possibility that there is a stigma attached to the family as well, which they reject by turning on the person diagnosed with a mental illness. This idea comes through in Jean’s response: “I never get visitors when I’m in hospital because my family don’t support me...its like I’m written off, because I’ve got a mental illness.” This has a negative effect on the person’s sense of self-worth. As Jean said: “Sometimes you feel so low and you think ‘I don’t mean anything, to anyone.’”

The experience of being discounted as a person comes through quite strongly in the family context. Of all the participants, Jean seemed to have the greatest difficulty with her family, and this comes through in her comments: “They make nasty remarks...they talk about you, but not to you about your illness. It’s like they talking, you not here. When family and friends get together, they would talk about me, they wouldn’t talk to me.”

It seems clear that what is at work is a process of negating the person diagnosed with a mental illness, treating them as though they are children, or ignoring them. Participants displayed some indignity at this, suggesting in some way that they had a right to be treated as equals. Yet, because these are the people closest to the person, there seems to be greater difficulty in asserting one's rights. In this context, holding onto a positive self-identity also becomes more difficult, and participants seemed to begin to think that maybe they were unworthy.

Even in the context of an ostensibly positive response to the person on the part of the family, there was some sense that they (the participants) were being undermined. Towards the end of the second meeting, Ben described how the family may do too much for the person: "They think you can't help yourself, they think your needs, how can I say, you're...you can't do what a normal person do...they think you a invalid."

Leanne agreed with this: "I find that people become over-protective towards me, they try and make sure that I'm in the safest environment possible...I walked from home to a friend. Now they will say, 'Can't I give you a lift there?'" This may have the effect of reaffirming both the disability and the sense that the person diagnosed with a mental illness is different from others. Jean asked Leanne: "Trying to take over your life now?" In response, Leanne elaborated: "But its more like they don't know what else they can do to work out, make things okay for you. They now become ridiculous in their suggestions." These comments suggest some of the dimensions of the over-protective response on the part of some families to the presence of a person diagnosed with a mental illness. This came through quite strongly, particularly for Leanne, the youngest participant. It is interesting that Leanne touches on the possibility that the family is trying to do too much out of their own sense of helplessness.

Writers such as Marks (1999) and Watermeyer (2000) touch on this idea in relation to psycho-dynamic dimensions of disability, suggesting that it is a defence against powerlessness and sometimes aggression towards the disabled person.

Maria also touched on this issue. She said: "My mother said that she noticed that I was depressed, and I was not depressed at all, I was happy to be with her at that time and I was wondering how my mother could say I was depressed." This comment seems to reflect the idea that the family may at times make more of the illness, and attribute the person's actions to mental illness when that is not the reason. One possible reason for the family's response in this instance may be that this is an attempt to draw attention to the illness at all times, despite the fact that the symptoms fluctuate. In this way, the label is reaffirmed, and fixed, where the illness itself is not.

Leanne seemed to struggle to come to terms with this whole issue, in one sense seeing it as an attempt on the part of other people to reassure themselves: "Then they've done their bit, some of them might not be prepared to actually go and find out what your diagnosis is all about, so all that they do is just to do something so that ...to clear their conscience." But after considering the issue for a while, she suggested that they are merely trying to be helpful, saying: "But on the other hand, people are genuine, they just want to help with the situation." This suggests a tendency to vacillate between the felt sense that people's help has some negative dimension and the belief that these actions are motivated by genuine altruism. This latter may reflect either a desire on the part of the person diagnosed with a mental illness to believe in this altruism or a learnt understanding that the family is good, and therefore does not bear the individual ill-will.

In the same workshop, Leanne suggested that the situation was easier to deal with when the people involved were closer to you:

With my family, when they become overprotective, I speak up and actually say 'Listen, in that situation I can actually deal with this thing on my own.' But sometimes with people who are outside of your family, your friends ...you're sort of careful to be honest with them and say 'you're doing too much for me now,' because then you sound ungrateful. It does sometimes make me feel very awkward...(you can't be absent for a while) you can't get flu...you can't have a physical illness without people thinking twice.

Leanne also felt something verging on distrust on the part of other people. This expressed itself in hyper-vigilance where she was concerned, as an expression of over-protectiveness. In Group One's second session, she said:

People... that knew me before I was diagnosed, knew what my abilities are, but as soon as I was diagnosed, they would not ...shy away from talking about it, but yet they would treat me as though they must make sure I can do a thing. They would give me the scope to do it, but they would keep watching.

This comment reflects the ultimate effect of this confusion, a double-bind that forces the psychiatrically-impaired individual to play the part of the disabled person for fear of upsetting others. They are, in a sense doing what Ebrahim describes as: "Playing roles that fits the description." This 'creates' disability within the individual. It is also something that the participants tended to reject, although it was a somewhat tricky situation, owing to the fact that it is difficult to distinguish from genuine altruism. In a sense they may feel that they are rejecting the kindness of others. This suggests that ultimately, the 'kindness' may in fact be the most undermining issue a person experiences.

Linked to this idea, there was also the suggestion that others view all illness as being somehow linked to mental illness, in the sense that any illness or absenteeism is attributed to mental illness. Jean explains this, and the emotion it induces: "I get very angry when my friends, like I've been in bed for two weeks, I had flu. Now the first thing that came to their minds was, 'Were you in again Jean?'" Potential reasons for this were suggested, including a voyeuristic interest in the mentally ill. Leanne also identified the possibility that particularly her parents felt the need to care for her, which echoes a suggestion from disability studies that the creation of dependency fulfils an intra-psychic dependency need on the part of the carer (Watermeyer, 2000).

Jean identified the voyeuristic aspect of other people's interest:

Say for instance now some child or some teenager is being sexually abused by one of the family members. People is not concerned about that how that child is feeling, they more interested in the juicy bits of the story. Now this is exactly how it happens (with mental illness)...and it makes me angry...if you not interested in my well-being, just shut-up. They just being inquisitive or busy-body. You can sense that.

Leanne said:

When the parents are involved in taking care of the individual for a few years, and they now giving the person a chance to ...try a relationship with someone...my parents would sit down with the guy and say 'this is what you need to understand' almost as though, if they gonna take a back seat, there has to be someone there to fill that space.

Participants felt that other people viewed mental illness almost as their defining characteristic. They, on the other hand, seemed to be saying that they were only mentally ill at times, but at other times were 'normal', i.e. the same as anyone else. Again, there is the sense that they are sometimes sick, but always disabled.

Reactions from the Community

Participants discussions of the way they felt when in the community seemed to suggest that they felt marginalised and stigmatised. The idea of stigma came through strongly, from the first session of Group One, right through all the sessions. In session two, Robert said:

Life goes down, down, down, 'cause everybody knows, 'No look there's something wrong with this person'...*iets gaan af van haar* like I feel sometimes when I walk sometimes here...you can't swear at the people, because ...its their brain power upon yours....it might be too late (when you get to the psychiatrist) because you've come so aggressive.

This comment captures some sense of what it is like to live in the community with a mental illness. The discussions revealed the participants' experiences of rejection and stigmatisation in their communities.

Sophia identified the feeling of being unwanted: "And you think you're not wanted in the room, you're not wanted, nobody wants you." Jean agreed: "You feel there's no place in society for you." This idea of there being no place in society for the individual once they are diagnosed could feed into the idea that there is a need to hide the illness, and that it is preferable to associate with other service users. Overall, the societal response to mental illness was characterised by the idea of stigma. Stigma reinforces the idea that there is something fundamentally wrong with the individual, and shapes others' interactions with them.

Participants also exhibited an expectation of hostility on the part of those in the community, and attributed their negative actions towards them in terms of their illness. For example, in session three Daphne felt that someone, "Took advantage of me, 'cause he knew I'm

disabled.” Jean also said: “In society already you are rejected.” Some of the participants seemed to feel that it was their responsibility to challenge this trend. In summing up her evaluation of what she had learnt during the course of the workshops, Florence said: “We have to open up...they just have to accept us...and they are only going to do it if we are going to take action.” Jean had expressed similar feelings in Group Two's third session: “If we don't allow people to walk all over us, they won't walk all over us...if I'm gonna allow Davyd to walk all over me, he will do it.” Again, it seems clear that there is an expectation of hostility on the part of others. What also seems clear is that, in contrast to dealing with the family's reactions, when dealing with responses on the part of the community, participants found it easier to be assertive. In the first session of Group Two, Florence had made comments on this theme:

Of course they will treat you like, ‘Ag, you won't cope, your not supposed to be there, ‘cause you can't sit here, sit there where all the VIPs are sitting, you see. They will always push you down, knowing that you don't have enough up here (points to her head) to manage to do that.

I said: “So they think you, they say if you're mentally ill also, you're stupid as well?”

To which she responded:

That's right, your stupid ja. You know something, sometimes mentally ill people act funny you see. You see like maybe somebody wipes their hand with a handtowel, whatever's there. And then because they know that you're suffering from a mental illness they look at you and think, “Are you mad?”

This response also touches on the tendency on the part of those in the community to conflate mental illness and stupidity, possibly a result of confusion over the difference between mental retardation and mental illness.

In the other group's first session, Daphne made a comment which suggested that she also felt that mental illness was unique in terms of the stigma which it attracted. She said: "You can have TB, AIDS, you can have cancer, they gonna treat you like normal. But the moment they hear you got schizophrenia (or other mental illnesses), then they withdraw from you". In the second session, after discussing the scenario set in a community care facility; Leanne explained how stigma was also a feature of mental health services, particularly after the combining of mental and other health services. She said: "Everybody knows that *that* door is...the psychiatric sister." Later, she said: "The whole stigma is 'she's coming from that door, that means she comes for psychiatric treatment, so you can't expect her to do otherwise...but I come from that same door, and I do the ...normal thing that they're doing." What comes through in these comments is that participants have had the experience of being stigmatised within the community, having been labeled by others. This labeling was identified by participants in both the employment situation, and in the community.

Participants seemed to have a good grasp of what their rights were, and were able to identify situations where they felt their rights had been violated. It was also felt that others perceptions of people diagnosed with mental illness played a strong role in shaping people's reactions to them as people diagnosed with mental illness. One area in which this was felt to be particularly evident was in the area of employment. The discussions in some way revealed that it is easier to assert one's rights in more formal interactions, when dealing with people that are not close to the individual. For this reason, labeling by the community, and rights issues in relation to employment and the mental health services were more easily understood and discussed. What was more difficult was making sense of how rights impact on the person's interactions with those close to them, such as family members. Leanne suggests that it is easier to tell family members that they are doing too much for you. But it is more

difficult when dealing with close acquaintances or friends. It seems that, even when there is a sense that one is not being treated correctly, it is difficult to make claims for one's autonomy and rights when you care about the other person, or feel that their actions are motivated by kindness. This adds significant complexity to an understanding of rights which rests on the assumption that knowledge of rights is all that is needed for rights to be claimed.

The Value and Content of Rights

This section examines some of the discussions that centred specifically on the issue of rights. Overall, having rights was felt to be important, and participants said that they could assert their rights. They identified a lack of awareness about their rights as a major factor in their not being granted their rights, both on their part and the part of others. What came through in the discussions was a sense that, while participants had a decent sense of what they should be entitled to, they expressed doubts about their ability to negotiate for these. It also became clear that there was a gap between participants' sense of entitlement, and their ability to frame this sense of entitlement in 'rights jargon'. When this rights jargon was made use of, it was generally in connection with issues surrounding treatment, in both the institution and to an extent in the community, or in relation to the issue of employment. There was greater difficulty in framing their experiences in inter-personal relationships in terms of rights, although the sense of entitlement came through strongly in the discussions.

Leanne made a comment in the fourth workshop which suggests how the way someone diagnosed with a mental illness is treated by other people has an impact on their experience of rights.

I just feel that, in terms of mental illness, rights are violated easier than someone (without mental illness). Our rights are violated easier and then we are made aware of

it...because people so easily treat you as a lower being...the way we treat someone, that comes back to us.

This suggests the idea that those diagnosed with a mental illness are vulnerable to rights abuses. The stigma and the way those diagnosed with a mental illness are viewed by society contributes to this. Critically, what Leanne is suggesting is that, given an ostensibly widespread view of the person with a mental illness as a “lower being”, it becomes possible for members of society, including the family members and mental health system staff, to ignore the concerns and complaints of those diagnosed with mental illness. However, the workshops revealed that this was not felt to be an acceptable situation, and there seemed to be a desire for change.

What became clear was that participants were concerned that others should treat them as ‘normal’ people, i.e. as they would treat anybody else. Maria said: “You must tell them that they must treat you right because you are the same like the other people.” Florence suggested that, “its all about a lack of understanding...we must just make them aware, its just like any other thing...we are entitled to be treated like any other person.” These comments made in the second groups fifth session echo Ebrahim’s comments in the very first session: “I just want to be treated ordinary”. This was perhaps the single most common response, that they should be treated the same as any other person. This points to the way others’ responses to them as persons diagnosed with mental illness are critical to an understanding of rights. It links with the idea that having human rights reflects an assertion of worth, and concomitantly, that not having these rights means that the person is “not fully human” (Strong, 1980, p. 36).

A clear concern for their ability to make their input heard was evident in relation to treatment - “you want him to listen to you”. This was an area in which there was a strong understanding

of rights, and considerable interest. For this reason, the participants expressed the desire to learn more about the Mental Health Care Bill.

The following comments were made during a general discussion on rights, in Group One's session four. Ebrahim said: "A consumer is supposed to have rights on medication, rights to decision-making." Jean agreed, saying: "To make decisions for yourself, not necessarily just at home, in a public place, hospitals, whatever." She went on to say: "I can decide whether I want treatment or not."

During this discussion, Jean said that at home, "its my decision to do things in a certain way" and it should be the same in the hospital. Yet the clear concern was for the right to be heard. As Jean said: "I have the right to be heard." This idea ties into the idea of worth mentioned above, since it seems clear that being heard is tied to an assertion of the validity of ones opinions. Consequently, by ignoring the input of the person with a mental illness, there is an inherent statement that their opinion is not valid. It is in this area that rights were strongly advocated for. Leanne's experience, discussed in the same session, was relevant here.

Leanne said:

I'm not sure really how the rights work once you've been hospitalised. I just felt that...I got the feeling that my rights had been violated, I was given a sleep injection, then I slept for three days, and ...they wake you up for every meal.

Jean interjected, "and you half asleep."

Laughing, Leanne agreed:

Ja, your face in your plate. So my thing is, there was no contact made...if they going to argue that I was a minor at the time, there was no contact made with my parents to actually confirm that they were going to do this...in things like those, I'm not sure whether your rights come in or not?

What is evident from this incident is the confusion which a lack of consultation results in. There was the suggestion that hospital staff may have felt that they were wasting their time consulting with the person in a psychotic state. However, participants said that they were still aware of what was going on around them on some level, and the lack of explanation contributed to their own fear and anxiety in the admission procedure in particular.

The participants also felt that, if at any time they were able to express their concerns, their rights should be taken seriously. Leanne said, later in session four: "If you are able to refuse treatment at any given time, somewhere you rights must be able to come up." She went on to say, in relation to her experience outlined above:

I felt that, even if you are how high, there is some part of you that can grasp ...what you been told. Even if they felt that they wasting their breath, if they at least explain what this injection was, what its gonna make you feel, what the procedure's involved. They treat you as though you are so out of it that nothing is gonna register, they gonna waste their energy on you.

This incident also illustrates something of the confusion that persists around rights for those diagnosed with a mental illness. While this may be partly due to the lengthy drafting process that the Mental Health Care Bill has undergone, in which both staff and patients may have experienced some confusion, it is also clear that there is insufficient understanding 'on the ground' about rights, and who has what right etc.

As Robert said at the start of that workshop: "I don't know what rights are because nobody told me." In Group One's final session Ebrahim explained a practical consequence of this:

And the, at hospital also uh, when I went to go and fetch the medication, I didn't know about all these rights that was for us...so I can pinpoint out to them so uh "hey

listen here, these are my rights, don't violate it. This is what stands in the Constitution.

However, there were some contested areas, as well as some confusion. In Group Two's session four, Florence said: "He's got a right to act aggressive...because of his illness." Florence's comment suggests some of the confusion which people diagnosed with a mental illness may feel. This comment formed part of a somewhat lengthy discussion of a patient who was facing a disciplinary action because he had been disruptive at a work group. The participants debated and negotiated how to make sense of this, since it involved a negotiation between the rights of one individual with the rights of the other members of the work group, as well as the organisation and its staff. What emerged was the feeling that mental illness entitled the individual to act a certain way, because their behaviour was the fault of the mental illness. The group did not however reach a consensus, reaffirming the intractable nature of the rights issue, in which negotiation between various interests is inevitable, and exceedingly complex.

Other comments suggested that rights involved a negotiation, if not a confrontation between the rights of the individual and the rights of others. In the very first session, Leanne said: "Because we are affected we talk about all our rights, ...and we forget that the employer still sits with the right to get the work done. Or at least the responsibility to have to get the work done." Rights were also felt to come into the interpersonal sphere, as Maria pointed out: "I've got a right to tell my boyfriend I've got a mental illness. If he don't want me he can leave" I felt that this comment was somewhat remarkable, since Maria had come into the group being quite shy and withdrawn, and during the course of the discussions, had become more assertive.

I asked participants how having human rights made a difference to them. Their responses suggested that rights are useful in everyday social situations, and thus the idea that rights can be regulated through the use of social sanctions, rather than legal ones, does seem to have some merit. These comments were made in Group One's fourth session, during the general discussion on rights. Ebrahim said: "Well then we all feel part of the society...and we can integrate." Jean pointed out that: "But they're (the doctors) aware of our rights... they aware, you must just make sure its happening"

She went on to say: "You just tell them: 'Listen here, it's my right, you not doing me a favour, this is my right that you must explain to me'." Leanne agreed with Jean's observations: "That's the big thing, its when you aware that...at this present moment this guy's violating your right not to do the following, then you make him aware that you know this, and that you challenge him." Ebrahim suggested: "The public must also be educated about things."

Later, Ebrahim suggested that society was becoming more aware of rights as a whole: "There's notices...by the hospital, the rights of patients and also the rights of the workers, GP's, so I think it will have an impact on society as a whole."

And later, he went on to say:

They shouldn't violate the law. As a citizen of this country, I feel my rights should be ...I should be listened to, it must be taken into consideration, 'cause I'm a human being. And I don't want to be hurt at all times.

Here again, there is a reaffirmation of the idea that the person diagnosed with a mental illness is a "citizen" i.e. a member of society, "a human being". This comment also struck me as somewhat poignant, with the experience of being "hurt" seeming to underlie the need to

affirm one's rights. In the final 'evaluation' session, Maria explained that the workshops had led to her feeling more confident to assert her rights. She said: "I've got that feeling now, I can do it. I've got the right to do that." Florence agreed with Maria's evaluation of herself: "And before that she used to do everything, everything in the house."

In the general discussion on rights, Ebrahim brought up the issue of involuntary incarceration, touching on an issue that continues to cause concern and confusion for all concerned with the rights of those diagnosed with mental illness. Jean's response may be quite close to the actual situation. Regardless of this, her response, that the person with a mental illness has no rights in this instance, suggests something of how such a situation is experienced by the person concerned, who is also suffering at that time from the symptoms of their illness. Ebrahim said: "My mum did take out...an interdict against me...so the police took me away." Leanne was confused as to how rights came into that situation: "Do you have any rights at that moment?" Jean's response suggests something of how the situation is experienced: "No" (laughs).

Yet there remain very real barriers to the situation which 'rights' are supposed to guarantee as well as doubts about the impact that rights have had on the actual material conditions of people's lives. There were also lingering questions about how effective rights could be. In session four, Leanne suggested that rights were not necessarily the best way of tackling how people treat those diagnosed with a mental illness. This calls into question the utility of rights as a whole, since they seem to have usefulness limited by situational factors. She said:

I think the big thing is you need to treat the patient fairly. Sometimes, its not so much about the right of the person as it is about treating the person...the doctor's bed-side manner, sort of. It starts with that. When that's in place, the rights just follow.

This tied in with a comment she had made in session two: “You don’t have to push it to the extreme of the rights.” Later, in session four, she said: “Rights won’t help people changing the way they treat you.” And towards the end of the general discussion on rights, she suggested again that rights might not be useful in every situation: “I sometimes think rights only protect you in places like the workplace.”

In the same workshop, she commented:

Because...there are so many rights, that you will never keep up with the rights that have fit in for you...and that you won’t be able to live your life making sure that all these rights are being fulfilled...but that you somehow make people sensitive to how to treat you, just by the way you treat others.

Her comments suggest the feeling that if you treat someone a certain way, you have the right to be treated the same way. Leanne went on to say: “They (the patients) have a right to be treated as a human being, regardless of their behaviour.” What becomes clear from these comments is that rights are most salient in the employment and mental health care spheres. This was also evident in participants’ responses to the scenarios. The first two scenarios elicited responses in which a sense of the rights of the person diagnosed with a mental illness could be ascertained. For example, there was a strong sense of indignity felt at the lack of consultation between staff and patients. This suggests that there is a feeling that the participants, as people diagnosed with mental illness, have a right to be consulted. This also came through in their discussions around how their family and other people treat them. In general, the overwhelming response seems to be that the right to be treated the same as other people was the right which participants most valued. This can be seen as a direct response to the experience of being disempowered through various situations and in various sphere’s, including financial (which relates to employment), social, the health system and the family.

However, there does seem to be a difference in terms of the response that the participants feel that they would make. It seems that there is knowledge of rights in certain situation, such as in the areas of employment and the mental health system. It also seemed clear that the participants had a sense of what they were entitled to. Yet, there were difficulties in expressing these ideas in rights jargon. In relation to family and close friends, there was an added difficulty in holding onto the sense of entitlement. In interpersonal situations, there seems to be more self-doubt, as people struggle to reconcile their own feelings with regard to what is the right way for others to treat them, and their feelings of dependency on others. This manifests as doubt over their ability to claim their rights, and doubt over their entitlement to make such claims. These issues raise questions over the participants' ability to actualise their rights.

It was also recognised that rights were necessarily accompanied by duties. One was, almost, a duty to prove oneself, to challenge the idea that as a person diagnosed with a mental illness; you are not as 'able' as others are. Leanne made a comment in the second session, which related back to her sense, expressed in the first workshop, that if given the opportunity, someone diagnosed with a mental illness should work extra hard to prove themselves.

That's why I always feel that its my duty, when I'm given a chance to do something, to show people that I can do it just as good and even better than someone else.

There was also a strong sense that those diagnosed with mental illness had a duty to educate others. This comes through in several of the comments above. This was linked to the view that there was little understanding of mental illness among members of the community.

It is possible that this issue is linked to the individualising of disability mentioned above. There is a sense in which the person with the disability has to make an argument for their own acceptability to others. The sense of duty relates to the idea of a 'sick role' as described by Parsons (1964). The sick person has an obligation to take all appropriate steps to get well. In this context, it could be argued the person diagnosed with a mental illness feels obliged to educate others about their condition in order to be accepted. This education also forms part of the ongoing attempt to make an argument for their equal status as people, and consequently, their entitlement to be treated as someone of equal worth - "I just want to be treated ordinary" (Ebrahim).

What these ideas suggest is that the participants felt that their rights are at times violated more easily than the rights of other people, due in part to the attitudes which surround mental illness. The concept of rights was understood, as there was a recognition of the fact that rights are negotiated, and that rights were associated with duties. Yet there was some confusion over rights, and in particular over what might be termed the 'jargon' of rights. What also emerged was some sense that there was a concern for the right to be heard, yet in interactions within close relationships, there was doubt over the utility of rights. This occurred despite the recognition that similar issues were raised in both these interactions and interactions in more formal settings, such as the community clinic or job situation. The implications of these issues need to be considered.

Summary

The participants seemed to struggle to negotiate a more positive identity, in the face of what they felt were negative views of mental illness which were pervasive in the community. This led to various strategies as well as various difficulties, which were discussed.

The particular difficulties were slightly different in each context. In the mental health system, participants seemed to struggle with persistent power differentials between patients and staff, which contributed to what they experienced as a disregard for their input and concerns. In the economic context, participants struggled with the issues of stigma and the creation of dependency, which a lack of money facilitated. Yet, in these two, more formal contexts, participants seemed to display a greater sense of entitlement. Similarly, in the community, while the experience seemed to be one in which they were stigmatised, there was a sense that they were entitled to better treatment, i.e. to be treated as normal. In contrast, the family situation and interactions in close relationships were characterised by greater difficulty on the part of the participants to hold onto their sense of what they were entitled to, although a sense of entitlement was evident. This context also seemed to facilitate the creation of dependency in the participants, through their infantilisation by family and friends, as well as the over-protectiveness of these important figures in their lives.

Overall, what emerged was a sense that rights represent a challenge to a 'discourse of difference' which seems to pervade the lives of those diagnosed with mental illness. For some of the participants, there seemed to be a resignation to the status quo. For others, there was still a measure of hope and excitement, because rights seemed to represent an assertion of their worth. Many of the comments included in the previous section seem to contain the assertion '*I am a human being*', and it is this idea which seemed to flow through the discussions of rights. There was a sense in which the experience of being someone diagnosed with a mental illness was an experience of being 'othered', and devalued in the process. My experience with the participants was characterised by their gratitude towards me, and it felt more that this expression of gratitude flowed more from an appreciation for my interest in

them and their problems than for what I had been able to give them in terms of information about rights. Consequently, the discussions on rights seemed to activate strong feelings of their own self-worth, and their desire to assert that worth, through the medium of rights.

The act of claiming rights also occurs in a social context, and this social context impacts on the participants' understandings of rights. The dynamic interaction between money, gender and race, as well as the power differentials that exist between doctor and patient all reinforce the idea that claiming rights is a function of an exceedingly complex array of factors. These issues have a bearing on participants' identities, their experiences as people diagnosed with mental illness, and the opportunities that they perceive for themselves.

It seems that, while there was an understanding of rights at some level, as a sense of entitlement and a negotiation between people, participants felt that their rights were more easily violated and they were not always able to express this sense of entitlement in terms of rights. What remains is to elaborate on these issues, paying particular attention to the processes which seem to be at work in shaping the sense of worth, or entitlement, which the participants displayed. It is in this area in particular that a psychological approach to the question of rights seems to be most appropriate. It is also necessary to interrogate the ambiguities and tensions between participants' sense of their rights, and the potential that exists to actualise these rights.

Chapter 7

Discussion

The preceding chapter divided the analysis into three different sections. This discussion will expand on the issues raised in the analysis, and examine some of the implications of the findings.

The Search for Positive Identity

The participants' discussions revealed the way that they struggled to negotiate their identity and integrate their diagnosis with their sense of themselves. The discussions suggested that there was a feeling that mental illness was part of who they were, but that participants felt the need to stress that they were not solely defined by their illness. It was this issue which seemed to underlie the struggle to negotiate their sense of themselves, and rejected others' attempts to define them in this way. Linked to this difficulty, participants also seemed to experience a need to be comfortable with themselves (and this extended to the need to be comfortable with their diagnosis) and the need to hide their illness. What seems apparent is that there was a desire to speak out, and assert one's worth, but that this was contrasted with fears of rejection and pragmatic social risks involved in disclosure, such as losing potential employment.

The argument that people were uncomfortable with their own diagnoses seems to reflect an individualising of the disability. The individualistic orientation suggested by Oliver's personal tragedy theory (Oliver, 1990) leads to the situation in which the person with an impairment must strive to diminish the negative consequences of that impairment. This relates to Parson's (1964) idea that the person in the 'sick role' has an obligation to strive to 'get well'. An interesting parallel within the current situation is that some participants seemed

to blame the person diagnosed with a mental illness for hiding their illness. This suggests that the denial of the illness is the real problem, which that person must strive to overcome. To accept this position, however, is to ignore the realities of the nature of the stigma of mental illness, and the fact that failure to disclose may have more to do with someone's own analysis of the risks and the potential benefits of disclosing. These ideas also highlight the way that various factors, such as economic concerns and fears of rejection, interact and shape the self-perceptions of a person with a mental illness. Many participants also expressed the preference for associating with other people that have spent time in institutions, or who have been diagnosed with mental illnesses. This can be interpreted as a form of 'self-ghettoisation', isolating people with mental illnesses from other people, thereby protecting them from being subjected to others' preconceptions. Participants felt that, in order to address this prejudice, people needed to be educated about mental illness. Yet it was unclear exactly who should be responsible for this

It is important to also make the point that other possible aspects of identity did not come through very strongly in the discussions. Race was one issue that was taken up briefly by a few participants, in discussing one particular example. Gender was not mentioned at all. However, issues of class and economic status were discussed in some depth. There are several possible reasons for these omissions. My position as a white male cannot be ignored. I was also in a position of power, as the researcher, with my own particular interests. This may have had the effect of silencing some areas that may have emerged as topics for debate. The other reason may have been that, having assembled the group according to one particular characteristic that they shared, i.e. the fact that they had all been diagnosed with a mental illness, it was this aspect of their identity that was made the most salient during the discussions. The issue of money tied directly into this, since it was suggested that economic

status was affected by their mental health status. The issue of financial positioning was also introduced because one of the scenarios dealt with employment, which led to discussions about money.

What seemed to come through in the discussions was a sense that identity was something which participants feel they need to negotiate constantly. This identity negotiation takes place in the face of what seemed to be negative perceptions of mental illness, and consequently of them, on the part of others. There is a sense in which the preconceptions about mental illness that permeate society (Philo et al, 1996; Ussher, 1991) have to be integrated into a sense of oneself, after the diagnosis has been made. The mentally ill person may accept the negative content of the label, which suggests that a negative view of the self will be internalised. This would be what was expected in terms of the ideas on the internalisation of oppression (Bartky, 1990; Fanon, 1967: 1993). Alternatively the person can find some way to reconcile their sense of themselves as a valued person, someone with 'worth', with their diagnosis. Both of these responses were to an extent evident in the experiences and responses of the participants.

The implication for rights is that there seems to be some sense of entitlement, which suggests that there will be some capacity to claim rights (Wellman, 1997). This also comes through in the rejection of the prejudiced views of them which participants seemed to feel evident in others' interactions with them. It must also be pointed out that the ability to make these claims seemed to be facilitated by the group context. The participants identified common features in their different experiences, and this in itself seemed to give them a stronger sense of what they actually should be able to claim for themselves.

Negotiating the Meaning of Mental Illness

Part of what is involved in coming to terms with the diagnosis was the need to also come to terms with what the idea of 'mental illness' means for people, both participants and others. Understandings of what mental illness means seem to be always negotiated against the backdrop of the idea of 'madness'. It was this idea which participants felt underpinned other people's views of them. They felt that they were 'mad', in the eyes of others, and not mentally ill. Interestingly, participants revealed that such a distinction does not exist in Xhosa, saying that people effectively called them 'mad' in that language, and that was the only commonly-used term. The label of madness was one which participants sought to reject. However, participants suggested that the community still conflated madness with mental illness, and we spent some time discussing the various meanings of 'madness'. It also became clear that the mental institution was associated with 'madness' and participants suggested that people view it as almost a storing house for the mad. It is this view which accompanies people into the community after being released from the institution.

Participants revealed that they adopted a number of strategies to challenge this negative view of mental illness. This relates to the preceding discussion, as it follows that, in attempting to make sense of their diagnosis, participants underwent a process of interrogating their own views on mental illness, and seeking to recast the negative content of such views in a more positive light. The first strategy was found in the participants' claims that mental illness was the same as any other illness. What comes through in this is an attempt to render the illness manageable, both for themselves and other people. The other issue involved in this claim is that illness is something that happens to a person, where madness *is* the person. Illness is a bodily dysfunction, and not related to a failure of them as a person, which seemed to be the alternative view. There was nothing fundamentally wrong with *them*, merely with their

bodies. The other important element in it being an illness is the sense that it can be controlled by medication, although the issue of relapses contradicted this. There is thus a strong political motivation for making such a claim. The counter-claim, that mental illness is unique, also rests on equally fundamental issues. For example, failure to acknowledge the impact of mental illness on one's life can result in the realities of the impairment being ignored (French, 1993), and this idea was also expressed in participants' discussions. It is clear that understandings of mental illness are tied to other people's perceptions of the person with a mental illness, as these claims reflect attempts to negotiate for a certain view of mental illness. Participants were trying to make their views understood and clear, to both themselves and me. The underlying issue seemed to be the need to make oneself acceptable to others, and this can be seen as a reflection of the participants' sense that in some way others found them unacceptable (see Marks, 1999; Watermeyer, 2000).

The second strategy for dealing with negative views of mental illness was observed when participants discussed times when they exhibited symptoms of mental illness, particularly in the case of those with Bipolar Mood Disorder, the behavioural symptoms of which in the manic phase are quite extreme. Participants seemed to make a distinction between their sick and well selves, and disavowed the times when they were sick as times when they were 'not themselves'. This suggests again the need to make themselves acceptable to people, because there is an attempt to assert that the actions at these times are not attributable to them, and therefore they should not be blamed or treated differently. This can be interpreted broadly as an attempt to negotiate worth, because it seems that there is an attempt to distinguish between the negatively viewed actions and the self, which has to be positively valued. However, it seems that others do not make this distinction, and treat them as if they were responsible.

There were a variety of other ways in which participants sought to fend off the negative perceptions of mental illness that they felt subjected to. One participant drew attention to the widespread prevalence of mental illness. Others argued that anyone could get a mental illness. Identifying the cause of the illness, attributed to either the person's physical makeup or their upbringing, also seemed to be part of this strategy. The final aspect of this strategy was the participants' tendency to suggest that when others labeled them as 'mad,' they attributed madness to that person. What these responses have in common is the idea that there is nothing wrong with them as people.

It is interesting that issues of class, race and gender are all tied up in the idea that mental illness can affect anyone. The application of the label of madness to others seemed to be facilitated by the ability of participants to make the claim that people who could afford it were able to be treated by private psychiatrists. The implication was that such people were able to avoid the stigma associated with the institution, and able to deny their mental illness. For this reason, it was possible for people to suggest that even potential employers could be suffering from mental illnesses, and other people that discriminated against them could be seen as being 'mad themselves'. The label of madness arguably becomes a function of wealth and privilege, because those unable to afford expensive private treatments are labeled, but those who can afford them escape such labeling. Again, at the heart of the issue is an attempt to reject the imposition of labels by other people and to negotiate a sense of one's own worth on the part of the participants.

These ideas have a bearing on the way participants attempted to make sense of the stigma associated with mental illness. Goffman (1968) points out that 'stigma' is a term from Ancient Greece, which has come to be associated with a moral flaw, a flaw with the person

as a person. Stating that anyone can get a mental illness or that you weren't born with the mental illness is stating that there is nothing wrong with you as a person, and consequently, you are of equal worth. As such, this claim for worth seems to represent the idea that the person has value to both themselves and others. The strategies that the participants revealed to make sense of mental illness reflect their attempt to negotiate a positive view of themselves, in the face of what were felt to be widespread discrimination and negative views of mental illness. The responses suggest that participants felt that they had to justify themselves in some way to other people, to apologise in some sense for their behaviour (Watermeyer, 2000). This suggests something of the way that participants felt they had to fight to have their worth as people recognised. In this way, the issue of rights comes through strongly as a claim for the value of a person to society (Strong, 1980), "solely by reason of being human" (MacFarlane, 1985, p. 3) i.e. as 'rights-bearers', there is an implicit recognition of their worth. It seems that in this abstract way, rights are clearly understood, even if the ideas are not expressed in terms of rights, but more in terms of what is right, i.e. the right way for others to treat them.

What seems clear from this is that participants seemed to struggle to find appropriate ways to define their experience, expressing their recognition of the way in which they are positioned by others' labels and perceptions. They sought to challenge this positioning by others. This is far from the passivity implied by the idea of 'internalised oppression' which was suggested in the literature (Bartky, 1990; Fanon, 1967: 1993), suggesting a pro-active negotiating of identity, and worth. In terms of rights, the search for positive identity suggests that participants do feel a sense of entitlement, a precondition for the claiming of one's rights (Wellman, 1997).

Negotiating Rights in Social Context

Having examined the strategies that participants developed to make sense of their identity and what they felt was the negative view of mental illness in the community, it is now possible to move onto examining some of the ways in which these ideas are played out in various contexts. What seems clear from the discussions on identity is that the act of claiming rights involves both an internal sense of one's own entitlement (Wellman, 1997) and certain external features of social organisation which enhance or hinder the ability of the participants to claim their rights. Rights occur in a social context and, as such, understanding rights involves understanding how people relate to their social context. Although in the analysis I divided this section into various spheres within which the participants interact with other people, it is important to recognise that these spheres interact and inform each other. For example, the perceptions of mental illness which exist in the community influence how people, such as health service staff and potential employers, relate to people diagnosed with mental illnesses. And, for example, a potential employer, basing his decision not to hire a person with a mental illness on the basis of preconceptions that exist in the community, impacts on the socio-economic status of that mentally ill person.

The Mental Health System

The first sphere within which interaction takes place is the mental health system. It is important to recognise that the influence of the mental health system continues into the community, where people receive their medication at community primary health clinics. And interactions with the mental health system also occur due to repeat admissions, the 'revolving door' scenario which has become a feature of deinstitutionalisation (Swartz & MacGregor, 2000). For this reason, the institution remains a feature of what is called 'community care', in the background of people's interactions with the mental health system in the community. In a

sense, the threat of 're-institutionalisation' underpins interactions with the mental health system.

The critical concern, in the current context, was the fact that participants felt there was a lack of consultation in both the diagnosis and the treatment of mental illness. This issue seemed to tie in with larger concerns regarding the sense that they, as people with mental illnesses were not listened to. What emerged was the participants' idea that people had a tendency to negate what they said, implying that their views were not valid. This seemed to translate in turn into a wider invalidation of them as people, which provoked attempts on their part to assert themselves.

The participants seemed to have a clear feeling in this context that they had the right to be consulted on medication and diagnosis. They also seemed to feel that they would be able to argue for such a position for themselves. This challenges the expectation, developed from the literature on internalised oppression (Fanon, 1967:1993; Bartky, 1990), that people diagnosed with mental illnesses are passive in their interactions with the mental health service. It also suggests that the idea of the mentally ill person as a consumer of such services may enjoy some currency (Morgan, 1997). However, this apparently positive perspective was contradicted by the experiences of participants in institutions, where they suggested that they were not always consulted, and the staff were able to treat them as they saw fit. This ties in with questions over the power of the patient (Haddox, 1986; Kapp, 1994). There seems to be a clear understanding of what should happen, i.e. a clear grasp of their rights and their entitlement (Wellman, 1997). Yet there seems to be some difficulty in actualising these, due in part to the persistence of power differentials between the staff and the patients.

Participants also linked the issues of the power of the mental health practitioners and staff in relation to the service users to pragmatic issues. Participants suggested that they were not able to make their meaning understood by the psychiatrist, for example, because of concerns that they would either be institutionalised, or have their Disability Grant taken away. This issue touches on the interplay between the creation of dependency, the stigma surrounding mental illness, and the difficulty involved in asserting one's rights. Thus, it is not necessarily only feelings of dependency, as would be suggested by an internalisation of oppression (Bartky, 1990; Fanon, 1967; 1993, Watermeyer, 2000), which create difficulties for someone seeking to assert their rights. The fact that they may have been cast as dependent, in real (economic) terms, by the prevailing social structure (as may be suggested by Oliver's, 1990, social theory of disability) also has a bearing on their ability to stand up for what they believe they are entitled to. In effect, the medical context provides a clear illustration of the ways in which internal factors, such as one's sense of self, interact with external conditions to influence the ability to claim rights.

The major form of treatment for mentally ill people in the community is usually medication. Participants revealed that they felt that medication acted as a reminder of their status as people with mental illnesses. They said that medication was used in the institution as a means of control, but that other people outside the institution also used the idea of medication, almost as a way of reminding them of their status as people with mental illnesses, tying medication to the identity of mental illness. The effect of this was to negate their attempts to negotiate positions for themselves, and interact with others on an equal footing. This suggests that medication is a critical issue in the lives of the participants even after they return to the community, as it positions them as mentally ill and consequently in need of either care or control. This suggests a strong link between medication and the creation of dependency

(Oliver, 1990; Watermeyer, 2000).

There is a sense in which the illness is constantly being referred to, through the medium of medication. This functions to distance the mentally ill individual from others, particularly those attending to the medication. Participants seemed frustrated by the constant reference to medication, which had the effect of discounting them and 'othering' them at the same time. It seems that in a very real sense, this formed part of a process whereby they were discounted as people, and the idea of them as mental patients was reinforced. Thus, mental illness comes to be their defining characteristic. As people in this category, but not as individuals, it becomes possible to project onto them the anxieties and disavowed contents which mental illness seems to evoke (Shakespeare, 1994). Participants also reported people attributing their actions to mental illness when they were not feeling ill at all. This suggests that others always view them as being mentally ill - the label is always there. This seems to contradict with their experience of themselves. The process of identity negotiation could in a sense be seen as a continued attempt by the person diagnosed with a mental illness to assert that they are not radically different from others, yet they suffer from an illness, which they feel is the same as any other illness. On the other hand, there are various groupings that see them as firstly people who are mentally ill, and then as people with unique characteristics. Thus, no matter how they are feeling, they remain 'mentally ill'. And subject to all that this entails.

Despite the negative reactions which medication evoked, the possibility of rejecting it completely was a complex issue. There seems to be a need to take the medication, because it controlled the symptoms of the illness. Yet it also evoked negative responses from the participants. What seemed to exist as an undercurrent to this issue was the idea that medication represented a form of bargaining. Participants' responses, in some way, suggested

that they agreed to comply with medication, and in this way contain the anxiety that they felt mental illness evoked in others (Marks, 1999; Watermeyer, 2000). In return, they felt that they should be treated in the same way as other people. For example, in the employment situation, it was argued that as long as a person complied with their medication, there was no reason that someone with a mental illness should not be hired to do any job they were qualified to do. The reported failure of other people to consistently make this distinction was another possible source of frustration for the participants.

Medication was, however, an area in which participants felt that they were able to assert their rights. They reported that they requested information on the medication, and the side effects of the medication, before they would accept it. However, particularly in the context of the institution, there was an apparent contradiction between this stance, and the reported experience of some participants who had been treated against their will, without receiving what they felt were proper explanations. This touches on a number of issues, such as the relative power of the psychiatrist in relation to the patient and the difficulty that the psychiatrist may have in making the distinction between 'genuine' objections based on a patient's risk-to-benefits analysis, and objections which are symptomatic of the illness (Kapp, 1994). The fact that the psychiatrist can institutionalise someone if they refuse to comply with their medication also calls into question how much power the patient has in this regard, and seems to contrast with participants sense of themselves as empowered in relation to medication (Haddox, 1986; Kapp, 1994).

The issue of traditional healing was also raised. The place of mental illness in traditional systems is somewhat contested, and it would not be appropriate to enter this debate here (See Swartz, 1998, for a detailed discussion). What is important is that the two participants who

had been in contact with traditional forms of healing both had very negative experiences. Once again, one of the central issues here was the element of choice. It was the families that felt that the illness could be dealt with using traditional methods of healing, and participants felt that they had little input. As with the issue of medication, the issue is complicated by the fact that the person is not likely to be well at the time. This issue is particularly relevant in a discussion of rights. The proposed legislation governing mental health care contains the idea that a person suffering from a mental illness has the right to appropriate care, with an emphasis on the patient playing a role in deciding what care is the most appropriate (Mental Health Care Bill, 2001). Yet the issue of choice in terms of defining 'appropriate care' often falls to others, and may not be what the mentally ill person would define as appropriate.

The issue is extremely complex. Traditional healing forms part of a framework of traditional modes of living, and consequently is very close to issues which are somewhat raw in South African society. The historical position places psychiatry in a position as the Western, 'white' treatment modality (Swartz, 1998). This is not to suggest that traditional modes of healing are the only ones seen as acceptable to black South Africans, as Maria's case clearly shows. Indeed, such a view "could be seen as lending tacit support" (Bodibe & Sodi, 1997) for the idea that psychiatric services are not needed for the black population, perpetuating the status quo of racially-skewed services (American Association for the Advancement of Science, 1998; Foster, 1990). Yet, it is the family who very often makes the decision, and the discussion in the groups suggests that they may opt for the traditional method.

This is problematic when these methods involve the abuse of the person. In a very real sense, the advances in patient's rights may not have been integrated into traditional systems, and part of the reason is that traditional healing does not have a clearly defined position in the

medical system (National House of Traditional Leaders, 2001). For example, if a traditional healer's place of work was not designated a health establishment, it would fall outside the control of legislation governing such establishments. The absence of legislation specifying where traditional healing fits in makes it difficult to regulate and control the care, and abuse, of patients.

The issue of traditional healing and mental illness foregrounds the relatively powerless position of the person with the mental illness, having to challenge the family and the weight of traditional authority at times. The issue goes to the heart of the debate around rights and mental illness, because the mentally ill individual's right to appropriate care is dependent to a large extent on who the person is that makes that decision, and who has the right to make such a decision. It must however be pointed out that similar issues are raised in terms of psychiatry, since the issue of faith healing as raised in the groups suggests that some people may prefer to choose 'alternative' treatment modalities. The issue seems extraordinarily complex, involving a negotiation between traditional views of mental illness and the dominant bio-medical model, the individual and the family, the individual and the community, and the community with wider South African society.

The Social and Economic Context within which Rights are Negotiated

The employment context was another area in which the participants experienced difficulties in actualising their rights. Participants felt that they could be employed, and should be employed. Thus, there was a sense of entitlement (Wellman, 1997). Yet, they were unemployed partly due to the stigma of mental illness, according to the participants. In this instance, it seems that dependency in real terms is created by social factors, exceeding the extent of the participants' impairment and marginalising them within society. Importantly,

the employment situation impacts on life opportunities, such as getting married, and raising a family. The issue reveals significant complexity in the area of rights - a person may have the right to have a family. Yet the practical implications of raising a family, such as the cost, inhibit people's ability to take advantage of their right. This issue ties in with Bobbio's (1996) assertion that social rights impose a duty on the State to enhance the capacity of people to assert their rights. Exactly how this could be achieved in this context remains to be seen.

The participants' economic status seems to play a role in how they made sense of their rights. Money was tied to fundamental issues of independence. It was also felt to have an impact on the way the participants were able to live their lives, and consequently, the opportunities that they perceived for themselves. A lack of money also seemed to tie in with a sense of their own powerlessness. As mentioned above, wealth was indicated as a factor in the quality of treatment that the individual was able to afford. And the nature of the treatment was felt to impact on the label people applied, since being treated in a public psychiatric institution was felt to be linked to the process of being negatively labeled on one's return to the community.

The issue of wealth in relation to rights seems to be a significant concern. In South Africa, our Constitution has a considerable emphasis on social and economic rights, reflecting the history of unequal development experienced by the different sectors of the population. As such, race and wealth inform and interact with each other, with income historically being distributed along racial lines. Foster (1990) points out how the racial divisions are also evident in the provision of mental health services. While steps have been taken to redress this situation, the situation remains that better services and facilities are located in previously White areas (American Association for the Advancement of Science, 1998). In terms of the

responses of the participants, a lack of money was linked to feelings of dependency and frustration.

Participants felt that the community plays a role in shaping the opportunities they experience. They reported feeling marginalised within the community, and that there was a strong stigma associated with mental illness. This impacts on the identity of the participants, in comments that suggest feelings of being unwanted and unworthy. Participants also felt that they were open to being taken advantage of in the community. But this was also contrasted with responses that suggested that people in the community simply had to accept people diagnosed with mental illnesses. Arguably, this form of thinking follows the rationale for deinstitutionalisation, in which the view seems to be that deinstitutionalisation must go ahead, and the community will naturally learn to be more tolerant. This contrasts with Reda's (1996) finding that community attitudes tended to remain stable, despite the presence of community care or 'deinstitutionalised' patients living in the area. Participants suggested that people recognised that the stigma was unacceptable, because, for example, potential employers sought to rationalise the reasons behind not giving a person with a mental illness a job.

The community reactions would seem to feed into the mental health system, because the staff are from the communities and were felt to share the views of the community. Similarly, it was suggested that potential employers did not hire people with mental illnesses because of the stigma associated with mental illness, and the lack of understanding about the nature of mental illness. What these issues underscore is the way in which ideas about mental illness feed into the opportunities that participants identified for themselves. The views of mental illness which participants felt existed in the community were cited as having a negative

impact on their ability to claim their rights and live their lives to the fullest extent possible.

There are several issues that emerge from these findings. The first point to make is that there seemed to be a strong grasp of what the participants felt they were entitled to, and what they could claim for themselves, which suggests that rights could be claimed (Wellman, 1997). The underlying claim was for people to treat them as 'ordinary people', with the implication that this was not what was happening at the moment. It is interesting that what seems to emerge as a fundamental value of the rights discourse for people with mental illnesses was the idea that rights seem to represent a way of challenging the participants' sense that other people held them in low esteem. This seems to be the result of the fact that rights are attributed to everyone solely by virtue of being human, and seek to protect people on this basis, as objects valued by society (see MacFarlane, 1985; Strong, 1980; Wellman, 1997). In this way, the fact that they have rights seems to be taken as an assertion that they are in fact the same as other people and of equal worth, and should be treated accordingly. Yet, there seem to be doubt when it comes to actualising these. Participants felt that their rights were violated easier than other people, because of the preconceptions that exist in the community about people diagnosed with mental illnesses. The experience of having one's views negated in interactions with others doubtless feeds into this sense that actualising rights is quite difficult. This suggests that some measure of the external marginalisation has been internalised, as participants "exercise harsh dominion over their own self-esteem" (Bartky, 1990, p. 22).

Participants seemed to generally have a clear sense of how rights functioned, and what their rights were, in most of the settings discussed. Yet, in discussions about interactions with family and friends, the issue became less clear. There seemed to be a struggle to establish a

sense of entitlement (Wellman, 1997) within the family, with people indicating that they felt entitled to certain things, but were not accorded them in the home. They also did not seem to see much opportunity for challenging this. Participants' discussions of the family context also revealed their experience of being 'infantilised' by family members, and of having their views negated (see also Watermeyer, 2000). What this suggests is that, particularly within the home, the creation of dependency was quite pervasive, and difficult to challenge (Oliver, 1990).

Fanon (1967:1993) suggests that the success of the oppression of black people in Martinique was due to the ways in which the family was enlisted as an agent of oppression. This idea seems to resonate with the situation of people diagnosed with mental illness. Ideas of the family as a nurturing force, (which arguably inform the move to community care and which place the burden of care on families - see Pilling, 1991 for a discussion) seem to exist uneasily alongside what participants seemed to regard as the family not treating them as they would like, or feel entitled to. The infantilisation of people diagnosed with mental illness within the family suggests that, in some cases, the family actually undermines the person's felt sense of their own abilities, rather than nurturing their potential. This suggests that disability is 'created' within the home (Oliver, 1990), as well as the fact that this creation of disability impacts on the self-identity of the participants in a negative way (Bartky, 1990; Fanon, 1967: 1993).

It is not just in relation to the family that people with a mental illness struggle to negotiate their sense of themselves, and their rights. In other close relationships, there seems to be a struggle to make themselves and their sense of themselves understood. Where, in dealing with the mental health system, for example, there seems to be a more strongly felt ability to

assert oneself, when interacting in close relationships this sense is lacking. Critically, there seems to be a stronger doubt about what they are entitled to claim (Wellman, 1997). This ties in with the idea that people released from mental institutions may doubt their own abilities (Wright, Gronfein & Owen, 2000). Foucault draws attention to the microscopic workings of power (see for example Foucault, 1967, Foucault, 1972:1976). What seems evident in this context is that, in everyday interactions, other people are felt to impose labels on those diagnosed with mental illnesses, and treat them in a certain, negative and undermining way. It seems that it is possible to reject this process when dealing with strangers, such as in the health system, the employment situation, or even in the community at large. However, it is less easy to reject the imposition of negative ideas of one's worth when those ideas come from the people closest to the individual (Fanon, 1967:1993). The idea of the Panopticon (Foucault, 1980), the internalised prison, becomes salient here. It is not necessarily just that the individual becomes their own prison warder, but that those close to them act in this capacity, undermining their claims and their sense of worth. The participants seemed to suggest that, in interpersonal interactions, people close to them positioned them in a range of ways, and this was not easily challenged. One reason for this would be that such people are the ones who know you best, and as such, their claims about the individual and their entitlements will seem to have greater validity.

The issue of being defined solely on the basis of having been diagnosed with a mental illness was also evident in the context of family and other close relationships. While participants sought to explain that mental illness was part of who they were, but not the whole, it seems that even the people close to them did not always make this distinction. What is equally important is that, while in other contexts participants seemed to be able to challenge this and reject the pejorative labels imposed by others, this seemed less easily accomplished when the

people applying the labels were close to the participants. The implication of this is that asserting one's rights in the context of interacting with one's family and friends is less easy than when one is interacting with others. Indeed, there were questions over whether 'rights' were of any use in this context.

Another way in which the family and those closest to the participants seemed to undermine them was found in examples of overprotective behaviour on the part of others. One participant suggested that this functioned as a way of reassuring family members that they had done something to make life easier for you. What the issue of over-protectiveness reveals is the tendency on the part of those close to the person with a mental illness to create dependency in that person (Marks, 1999; Oliver, 1990; Watermeyer, 2000). The person with a mental illness is placed in the situation where they have to make a choice between sounding ungrateful or accepting the position of dependency. Writers on the psycho-dynamic dimensions of disability have suggested that such a response reflects an attempt by the helper to deal with their feelings of helplessness which disability evokes in them, and even their own feelings of aggression towards the disabled individual (Marks, 1999; Watermeyer, 2000). The infantilisation of the person with a mental illness and the over-protective behaviour of family members can perhaps best be understood in this light.

What is critical for the issue of rights is that such dependency undermines the person's ability to define a position for themselves. For example, a sense of their own abilities may be undermined (Wright, Gronfein & Owen, 2000). Particularly in relation to the family, this may impact on claims the person with a mental illness makes, for example in requesting to handle their own financial affairs (Wellman, 1997). What seems to be reinforced is the complex interplay between various dimensions of oppression, including internalised

oppression (Bartky, 1990; Fanon, 1967: 1993) and the person's capacity to assert their rights (Wellman, 1997). What an analysis of each of the contexts reveals is that there are, however, what might be defined as 'structural' barriers to people claiming their rights, such as the power differentials between doctor and patient and a lack of resources (Oliver, 1990). It is not merely internalised oppression (Bartky, 1990; Fanon, 1967: 1993) that hinders the assertion of rights. Yet, the effects of this cannot be ignored. This suggests that, in trying to enhance people's capacity to assert their rights, intra-personal, interpersonal and structural issues will need to be addressed. Excessive focus on internalised oppression runs the risk of leading to victim-blaming (Foster, 1993). Yet, on an individual level, it is possible to implement concrete programs aimed at empowering people to make use of their rights and challenge the internalisation of oppression. This suggests why such a focus might be desirable. Yet, and this emerges clearly from the discussions, there is a need to address, for example, the perceptions of mental illness which are felt to exist in the community.

Towards a Definition of Rights for the Mentally Ill

What emerged during specific discussions on the issue of rights, as opposed to general discussions on their lives, was the sense that participants felt that their rights were violated more easily than the rights of other people. In part this can be seen as flowing from what participants felt were the views in the community about people diagnosed with mental illness. In general, it seems that it is easier to violate someone's rights when they are viewed as being of less worth. It is interesting to note that a violation of human rights semantically suggests that the person violating their rights would to some extent view the person whose rights have been violated as non-human. Yet it is precisely this issue which comes through in an analysis of the views towards people with mental illness which are found in the literature, which trace an association between mental illness or madness (as a loss of reason) and animality

(Foucault, 1967). Pinel's comment that people who lose their reason have lost that faculty "by which man is principally distinguished from the beasts" (Pinel, 1806, in Porter, 1991, p. 12) conveys this idea. This serves to reinforce the idea that rights are a testament to the worth of people as human beings (Strong, 1980).

What became clear in the discussions was that the participants wanted rights to fulfill certain functions. Critically, the participants suggested that they wanted to be treated in the same way as other people, and that they wanted to be heard, particularly in the mental health system. It must be pointed out that this may have been a function of their awareness of these issues due to their involvement with CCAB. What links these ideas is some sense that rights represent a challenge to the way in which participants seemed to feel other people positioned them as 'Other' and as of lesser worth. The literature on the social construction of mental illness (Showalter, 1985; Ussher, 1991) suggested that people diagnosed with mental illness might have the experience of being made 'Other', and participants' comments supported this idea.

There was, however, some confusion expressed in terms of exactly what their rights were. It seemed to be the case that while the participants had a good sense of what was right, in terms of how they felt others should treat them, there was confusion around how exactly this related to rights, as set down in law. This suggests a lack of familiarity with the 'jargon' of rights. This issue is an important one, because it suggests both that participants were not as passive as an extreme reading of the 'internalised oppression' hypothesis might suggest (Bartky, 1990; Fanon, 1967: 1993). Yet at times, it seemed that participants were unable to make sense of the jargon of rights, or were unaware of it altogether. This awareness or felt sense of what is right should be tapped when trying to develop education programmes around rights,

since it opens up the possibility for making people aware of the relevance that rights have for them in their everyday lives.

Related to this issue was the participants' suggestion that they needed to be aware of their rights at the moment that their rights are violated, in order to be able to claim them. Participants suggested one problem with this, that they may in fact be too ill to claim their rights. This ties in with some of the problems identified by Kapp (1994) and McLachlan & Mulder (1999) on the difficulties involved in patients claiming their rights while institutionalised. This issue also relates to the lack of familiarity with rights as a specific tool for their protection, as it may not always be possible for people to frame their sense of injustice in terms of rights. This impacts on the provision of both community and institution-based care. Being able to frame the issue adequately as a rights abuse has a significant bearing on the steps that are taken to rectify the situation.

It was also suggested that rights involve a negotiation. Participants recognised that other people had rights too, including potential employers and medical staff etc. Consequently, they recognised the need to respect others' rights, if their rights were to be respected. This suggests that there is unlikely to be a dogmatic application of rights, thereby avoiding the situation that Glendon (1991) warns of, whereby rights negotiations devolve into a stand-off between two opposing positions, with no potential for compromise.

The final issue which became clear when discussing rights was the sense that some participants felt that rights were more easily understood in the context of the mental health system and the employment situation (formal contexts), but that, in everyday interactions (informal contexts), the role of rights was less clear. There was a sense that rights, understood

as legal concepts, are an extreme measure, and consequently may have little value in regulating interpersonal relationships. Yet, it is also clear that the same emotional responses are present in both formal and informal contexts, suggesting that rights are relevant in both contexts. In the informal interactions with family and friends, the sense of entitlement seems harder to hold onto and for this reason, rights may go unclaimed (Wellman, 1997). It is this that may be at the heart of participants' reluctance to cast interpersonal relationships in terms of rights. Kapp (1994) suggests that there is a difficulty in expecting the legal system to exert control over the doctor-patient relationship. This difficulty is clearly even greater in the context of interpersonal relationships.

It is possible that Drewett's (1999) idea that rights can be enforced by "cultural sanctions" (p. 115) has some bearing in this regard. If it is widely felt that treating a person in a certain manner is unacceptable, then the possibility exists that social sanctions will be imposed on those that transgress. While Bobbio's (1996) claim that this reflects a 'weak' form of sanction is relevant, it could be argued that this would at least reflect an attitude that such rights are deserving of protection.

Yet participants suggest that their rights are easily violated, which suggests that such social sanctions are unlikely. Social sanctions are also less likely given the stigma associated with mental illness (Goffman, 1968; WHO, 2001, chap. 4). The implication of this understanding is that what would seem to be needed is an attempt to challenge the perceptions of people with mental illnesses that exist in the community. Negative views of the person diagnosed with a mental illness were felt to facilitate violations of the participants' rights by others. This suggests that there are inadequate social sanctions to make such protection effective. Wellman's (1997) comment that "only if the force of society actually did, or ought to, protect

a right could rights function to prevent or resolve conflicts between the individual members of society” (p. 5) is relevant here. What this suggests is that rights will remain an inadequate means of protecting the vulnerable unless efforts are made to challenge the underlying ideas that make violations of their rights possible.

Implications of the Study

What became apparent during the course of the research was that participants had a fairly good understanding of what rights were, and how they should be made use of. Yet this was at times contrasted with what seemed to be a lack of familiarity with the ‘jargon’ of rights. Thus issues were not framed in terms of what people had a right to, and the word ‘rights’ did not come up very often in the speech of the participants. If campaigns educating people about their rights are to be effective, care needs to be given to making clear the link between people’s sense of what they are entitled to and the ways in which these issues can be framed as claims for what they have a right to.

The research suggests that the participants felt, to an extent, able to assert their rights in ‘formal’ settings, such as the psychiatric institution and the employment situation. It is important to note that this reflects participants’ sense of what they would be able to achieve, and seemed, to an extent, to be removed from their actual experiences of difficulty actualising their rights in these contexts. It is important to remain cognisant of the structural constraints which affect their ability to assert their rights, such as the power differentials between doctors and patients. Yet when dealing with people in less formal contexts, there seemed to be greater difficulty in holding onto the sense of what they were entitled to. This became especially clear in discussions about relationships with friends and family members. What this suggests is that there should be attention devoted to the micro-context within which

rights are enacted. This idea ties in with Foucault's (1980) focus on the micro context of power relations.

What seems clear is that some sense of empowerment is needed in order to make claims for what the individual is entitled to, in the face of objections from the people one cares about. Such empowerment should also facilitate communication between the mentally ill person and the family at times when the person has a higher level of functioning. In so doing, it may be possible for the person diagnosed with a mental illness to convey their experience of the way the family treats them when they are ill (and at other times, when they feel the family fosters a sense of incapacity in the person diagnosed with a mental illness). It seems that at an interactional level, the way that power works is complex, and rights are one method of asserting power. This suggests that merely educating people about the language of rights will not necessarily be sufficient to enable them to assert their rights. The group context offered the opportunity for participants to integrate their everyday experiences with their rights. This method suggests itself as a potentially useful way of helping people with mental illnesses make sense of their experience and develop a sense of empowerment. This sense of empowerment was observed to emerge during the course of the workshops. The development of a more positive identity may also be more likely in the context of a group, because participants seemed to draw strength from sharing their experiences and finding common features, as well as learning how others dealt with difficulties that they had experienced.

What also seems clear from the study is that the participants felt that there is a strong stigma associated with mental illness, and that they are discriminated against because of their mental illness. It was felt that this contributed to their marginalisation within society, informing the way that other people responded to them, and influencing the opportunities that the

participants saw for themselves. This suggests that there is a need to educate the communities about mental illness. The internalisation of such views also affects the participants' sense of their own entitlement, and challenging this stigma could lead to a more positive self-perception.

It is not just the community that needs to be better educated about mental illness. It seems clear that there is a need to educate the family about mental illness. Yet, care must be taken to remain cognisant of the family's belief system, as the discussion of other forms of treatment suggests. Particularly in South Africa, approaching community education on mental illness from a purely bio-medical perspective will be inadequate. The move to deinstitutionalisation is likely to place a burden on families who may already be struggling to come to terms with the diagnosis of a family member. Family members behaviour and need for care are likely to increase the tension within the home. Families need to be empowered to assist their mentally ill relations. To make this a reality, it is recommended that the family be involved as much as possible by the mental health system, to allay some of their fears and confusion. What is suggested is that efforts need to be directed towards fostering an environment within which all the parties can make themselves and their concerns understood. It emerged that rights were the result of a process of negotiation, and it is this negotiation which needs to be encouraged. Yet, as a negotiation, it must be recognised that all concerned need to feel able to express themselves as equals.

The concern to be treated as equals was what came through the discussions as the participants' strongest desire, and it was this that they seemed to seek from the rights discourse. This suggests that they do not feel that people treat them as equals at the moment. Community and family education around the issues raised in this thesis will hopefully go

some way towards challenging this trend, in which people diagnosed with mental illness seem to be regarded as having a diminished capacity. The participants suggested that they were not as disabled as they were treated, and that the way others treated them at times made them doubt their own abilities. Steps to challenge these processes would therefore be welcomed.

Recommendations for Further Research

As implied from the foregoing discussion, greater attention needs to be devoted towards educating the family and the community. This suggests that research needs to be done into how best to achieve this. What is also suggested is that a greater understanding of the perceptions of people diagnosed with mental illness needs to be developed. This research opened up questions around, for example how potential employers view people diagnosed with mental illness. Other questions relate to how the staff of health establishments dealing with the mentally ill view the patients, and how these perceptions influence the way they interact with them. Participants suggested that it was not always a matter of rights, theirs versus the staff's, which was relevant in their interactions with hospital staff. There concerns centred rather on how the staff treated them. It seems that participants felt that the way the staff treated them belied some antagonism towards them, and this issue needs to be explored. Factors such as staff frustration may also need to be explored as factors that impact on how aware of patients' rights staff at health establishments are.

Similarly, the way that the family interacts with family members diagnosed with mental illness is also suggested as an area that needs further study. This is an area of increasing importance given the increased reliance on the family to provide care that deinstitutionalisation seems likely to foster. If research can shed light on ways to defuse the

tensions that seem at times to exist between the participants in this study and their families, such research must be encouraged. For this reason, research devoted to empowering the family and all its members, particularly through the development of coping skills, seems needed.

More generally, this research highlighted the way that people diagnosed with mental illness feel marginalised within society. This implies that a greater understanding of the ways in which society responds to people with mental illness is needed, and the reasons for this would need to be examined. I would suggest that research is needed into exactly how mental illness is perceived, taking note of the possible anxieties which may underlie such views.

The final recommendation would be that the relationship between mental illness, indigenous healing and rights needs to be explored. This issue was merely touched on in this research, yet traditional views on illness and causation etc. are critical to an understanding of the experiences of a large proportion of people diagnosed with mental illness in South Africa. They also inform the ways in which the family and the community interacts with the person. As such, a greater understanding of the issues involved is necessary.

Conclusion

This study provided support for the idea that human rights, as a social phenomenon, should not be examined outside of the context of people's lives and social contexts. It offered the opportunity to examine the ways in which people's experiences impact on what they understand to be their human rights, as well as the meaning and emphasis that they attach to certain aspects of human rights. The result was a broader understanding of how people come to have the views they do in relation to human rights.

The literature on internalised oppression (Bartky, 1990; Fanon, 1967: 1993) suggested that, given the stigma and prejudice surrounding mental illness (WHO, 2001, chap. 4), people diagnosed with a mental illness would exhibit low self-esteem. This suggestion was supported by other research (Wright, Gronfein and Owen, 2000). Wellman (1997) suggests that rights will go unclaimed in the absence of a sense of entitlement, and a sense of entitlement is precisely what would be undermined if an individual questioned their own worth.

However, in the current context, it seems that the issue is more complex. The participants did not accept their position, and sought to negotiate a more positive identity for themselves. There were aspects of internalised oppression, such as doubts about one's worth, which manifested themselves at times during the discussions. This suggests that the process of identity negotiation is an ongoing one. But it seems that both external or contextual factors, and internal factors, such as self-esteem, play a role in actualising rights.

Examining rights in their social context reveals that there are various situations in which rights become salient. And the felt ability of the participants to claim their rights was to an extent dependent on the context. One reason for this seems to be that a sense of entitlement was easier to hold onto when dealing with more formal contexts, such as the employment situation and the mental health system. In interpersonal relationships, this was more difficult. What this suggests is that, in these informal contexts, there is doubt about what the individual is entitled to claim. This lends support to the idea that some degree of oppression becomes internalised. It also points to the difficulty involved in challenging the beliefs of those closest to the person with the mental illness.

The origin of rights as a legal concept also impacts on their utility in the context of interpersonal relationships. Rights were felt to be too extreme in this context. This suggests that rights are not seen as a way of negotiating interpersonal relationships, and that they are not subject to social sanctions (Drewett, 1999) in everyday interactions.

The examination of rights in their context also suggests that there are persistent structural factors that impinge on the ability of people to claim their rights. The intersection of race and class factors with issues related to mental illness was one example. These issues also interact with other existing arrangements of power, such as the power differentials between doctor and patient. For example, the psychiatrist's power is enhanced by his/her ability to restrict the freedom of someone with a mental illness (Haddox, 1986) and make recommendations regarding the Disability Grant. These factors were cited as reasons for not claiming one's rights. This suggests the link between external and internal factors in claiming one's rights.

Rights were felt to be a positive development, offering a way to challenge what was experienced as a pervasive discourse of difference. In the current context, certain rights issues seemed have particular relevance for the participants. The way human rights intersect with the mental health care system was a key concern, as was the way human rights inform employment circumstances. Yet, at a wider level, the ways in which participants framed their understanding of human rights seemed to suggest that the critical issue for them was equality. Participants demonstrated that they felt marginalised in society, for example in the employment situation, and social interactions. They also felt that their concerns were not heard, or ignored by the mental health service staff. This was traced to ideas in the wider society that position the person diagnosed with a mental illness as someone less than human

in many respects. For example, the idea that a mentally ill person has lost their reason implies that they have lost that characteristic which separates man from beast (Pinel, 1806, in Porter, 1991). Participants related how such an idea seemed to permeate people's attitudes to them as people with mental illnesses, and as a result they were dismissed as irrational.

Participants indicated that they felt discriminated against and alienated in numerous contexts in society. However, their discussions suggested that a sense of empowerment seemed to develop from having one's rights protected by a legally-binding code. It was this that came through as possibly the strongest value of human rights in the workshops. The participants seemed to draw strength from the fact that they had recourse to a higher body for protection. This feeling was to an extent facilitated by the group context. Having people who were in the same situation and had similar experiences seemed to empower the participants. The workshops seemed to work not only on the participants sense of what they were entitled to in terms of treatment by others, and by the psychiatric apparatus, but also in terms of what they were capable of. However, it is difficult to accurately assess to what extent this was a function of the group context or the discussions on rights. It would however seem that the opportunity to discuss these issues was something new to participants. It may be that empowerment can be facilitated by encouraging discussion groups which develop an understanding of the issues faced by people diagnosed with mental illness. Such group can both raise awareness and enable people to work together in the search for solutions to their common problems (Stein, 1997).

It is suggested that a greater understanding of the content and form of the discrimination against the mentally ill be developed. The interest in rights stems from the understanding of themselves as 'othered' by society. Challenging this may go a long way to countering the

problems, and ultimately may be more successful than pursuing a human rights agenda. Primary health care follows the dictum that 'prevention is better than cure' and this would seem equally applicable in this context.

The issue of human rights is more complex than a matter of codifying rights and assuming change will follow. I return to Foucault's (1991) statement that "liberty is a practice" (p. 245). The converse of this is that oppression is also a practice. To the extent that this is true, it becomes necessary to explore some of the ways in which the practices of society and individuals can be transformed to facilitate greater liberty for those diagnosed with mental illness. Rights do empower people, because they suggest the importance of any given individual within society. Yet proclaiming someone's worth is not the same as acting as if they had worth. It is at the level of practice where the true test of rights as a means of challenging power relations lies.

The process of the research allowed a potential for viewing the way participants made links between the events and experiences in their lives, and the idea of human rights. This research also shed some light on what is needed in order for rights to be actualised, and it is possible to try at this stage to make this clear. There needs to be knowledge of one's rights, as a necessary first step, and particularly some knowledge of the jargon of rights, with which the individual can express their sense of what they are entitled to. There also seems to be a need for a felt sense of capacity to assert one's rights. Yet at the same time, aspects of identity also become salient, and it is suggested that a felt sense of one's capacity to assert one's rights must also be accompanied by some form of actual capacity, in terms of economic and practical issues. What the research highlighted is that at times, when grappling with everyday 'bread-and-butter' issues, it is not possible to devote much attention to the 'esoteric' realm of

rights. Yet what is equally clear is that rights speak to the fundamental level of interactions between people, and it is this dynamic tension which came through strongly in the research.

The issue of rights for people diagnosed with mental illness is extremely complex. It involves issues of identity, and the place of the person in society. It also involves the way society responds to people diagnosed with mental illness, as well as the way people diagnosed with mental illness interact with those around them, and the institutions with which they come in contact. A variety of labels and a variety of experiences all impact on how people make sense of and make use of their rights. Yet amidst the complexity, what came through in the discussions with the participants was some sense that rights are a positive development, and there seemed to be a hope that they would enable the participants to challenge the negative way that they felt positioned by others. To repeat Florence's words: "We may live in poverty, but we've got our rights". This suggests that the negative outlook that seemed to emerge from the literature contrasted to an extent with the opportunities for improvement that the participants identified.

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Appendix A: Scenarios

Scenario 1

John, a forty-two year old man, was admitted to Valkenberg, where he was diagnosed with schizophrenia. He was released after three months. He resigned from his job after being admitted to Valkenberg, and has been unemployed for two years. He goes for an interview with a large department store. The interview seems to be going well, John is qualified for the job and he actually recognises Mr. Daniels, the interviewer, since they both went to the same school. Mr. Daniels asks John why he left his previous job, and John tells him about being diagnosed with schizophrenia. A short while later, Mr. Daniels terminates the interview. When John phones back a week later, he is told that he did not get the job.

Scenario 2

Karen was diagnosed with a major depressive disorder, and spent some time in Stikland hospital. One day, while waiting for her medication at a community clinic in Bellville, a woman approaches her, and they start to chat about the long wait to see the doctor etc. The woman asks Karen who she is waiting to see, to which Karen replies that she is waiting to see the psychiatrist. On hearing this, the woman stops talking and moves to the other side of the clinic.

Scenario 3

Jane is thirty years old, and was diagnosed with bipolar mood disorder several years ago. She met Peter at a friend's party and they started chatting. Over the next few weeks, they meet each other a few times in the company of friends and then start to date. One day, Jane explains that she can't meet Peter for lunch because she has to see her psychiatrist. Peter asks why she is seeing a psychiatrist, and she explains the reason. He also asks her why she did not tell him sooner. They continue to date for a few weeks, but after a month, Peter says that he can't see a future for them together, and they break up.

Appendix B: Chapter 3 of the Mental Health Care Bill, 2001

CHAPTER III**RIGHTS AND DUTIES RELATING TO MENTAL HEALTH CARE USERS****Application of chapter**

7. (1) The rights and duties of persons, bodies or institutions set out in this Chapter are in addition to any rights and duties that they may have in terms of any other law.

(2) In exercising the rights and in performing the duties set out in this Chapter, regard must be had for what is in the best interests of the mental health care user.

Respect, human dignity and privacy

8. (1) The person, human dignity and privacy of every mental health care user must be respected.

(2) Every mental health care user must be provided with care, treatment and rehabilitation services that improve the mental capacity of the user to develop to full potential and to facilitate his or her integration into community life.

(3) The care, treatment and rehabilitation services administered to a mental health care user must be proportionate to his or her mental health status and may intrude only as little as possible to give effect to the appropriate care, treatment and rehabilitation.

Consent to care, treatment and rehabilitation services and admission to health establishments

9. (1) A health care provider or a health establishment may provide care, treatment and rehabilitation services to or admit a mental health care user only if-

(a) the user has consented to the care, treatment and rehabilitation services or to admission;

(b) authorised by a court order or a Review Board; or

(c) due to mental illness, any delay in providing care, treatment and rehabilitation services or admission may result in the-

- (i) death or irreversible harm to the health of the user;
- (ii) user inflicting serious harm to himself or herself or others; or
- (iii) user causing serious damage to or loss of property belonging to him or her or others.

(2) Any person or health establishment that provides care, treatment and rehabilitation services to a mental health care user or admits the user in circumstances referred to in subsection (1)(c)-

(a) must report this fact in writing in the prescribed manner to the relevant Review Board; and

(b) may not continue to provide care, treatment and rehabilitation services to the user concerned for longer than 24-hours unless an application in terms of Chapter V is made within the 24-hour period.

Unfair discrimination

10. (1) A mental health care user may not be unfairly discriminated against on the grounds of his or her mental health status.

(2) Every mental health care user must receive care, treatment and rehabilitation services according to standards equivalent to those applicable to any other health care user.

(3) Policies and programmes aimed at promoting the mental health status of a person must be implemented with regard to the mental capacity of the person concerned.

Exploitation and abuse

11. (1) Every person, body, organisation or health establishment providing care, treatment and rehabilitation services to a mental health care user must take steps to

ensure that-

- (a) users are protected from exploitation, abuse and any degrading treatment;
- (b) users are not subjected to forced labour; and
- (c) care, treatment and rehabilitation services are not used as punishment or for the convenience of other people.

- (2) A person witnessing any form of abuse set out in subsection (1) against a mental health care user must report this fact in the prescribed manner.

Determinations concerning mental health status

12. (1) Any determination concerning the mental health status of any person must be based on factors exclusively relevant to that person's mental health status or, for the purposes of giving effect to the Criminal Procedure Act, and not on socio-political or economic status, cultural or religious background or affinity.

- (2) A determination concerning the mental health status of a user may only be made or referred to for purposes directly relevant to the mental health status of that user.

Disclosure of information

13. (1) A person or health establishment may not disclose any information which a mental health care user is entitled to keep confidential in terms of any other law.

- (2) Despite subsection (1), the head of the national department, a head of provincial department or the head of a health establishment concerned may disclose such information if failure to do so would seriously prejudice the health of the mental health care user or of other people.

- (3) A mental health care provider may temporarily deny mental health care users access to information contained in their health records, if disclosure of that information is likely to-

- (a) seriously prejudice the user; or

(b) cause the user to conduct himself or herself in a manner that may seriously prejudice him or her or the health of other people.

Limitation on intimate adult relationships

14. Subject to conditions applicable to providing care, treatment and rehabilitation

services in health establishments, the head of a health establishment may limit intimate relationships of adult mental health care users only if due to mental illness, the ability of the user to consent is diminished.

Right to representation

15. (1) A mental health care user is entitled to a representative, including a legal

representative, when -

(a) submitting an application;

(b) lodging an appeal; or

(c) appearing before a magistrate, judge or a Review Board, subject to the laws governing rights of appearances at a court of law.

(2) An indigent mental health care user is entitled to legal aid provided by the State in

respect of any proceeding instituted or conducted in terms of this Act subject to any condition fixed in terms of section 3(d) of the Legal Aid Act, 1969 (Act No. 22 of 1969).

Discharge reports

16. The head of a health establishment must, in a prescribed form, issue a discharge

report to the user who was admitted for purposes of receiving care, treatment and rehabilitation services.

Knowledge of rights

17. Every health care provider must, before administering any care, treatment and

rehabilitation services, inform a mental health care user in an appropriate manner of

his or her rights, unless the user has been admitted under circumstances referred to in section 9(1)(c).

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